MAKING FRIENDS: DEVELOPING RELATIONSHIPS BETWEEN PEOPLE WITH DISABILITIES AND OTHER MEMBERS OF THE COMMUNITY

The G. Allan Roeher Institute

93-01262/

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Canadian Cataloguing in Publication Data

The G. Allan Roeher Institute
Making friends: Developing relationships between people with disabilities and other members of the community.

Includes bibliographical references.
ISBN 0-920121-89-6

Issued also in French under the title: Ainsi se fait l'amitié: cultiver les relations d'amitié entre les personnes handicapées et les autres membres de la communauté.

1. Handicapped - Psychology. 2. Friendship.
I. G. Allan Roeher Institute

HV1568.M35 1990 158'.25'087 C90-095050-1

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The G. Allan Roeher Institute

Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment

The G. Allan Roeher Institute has two major goals:

- to identify and anticipate future trends that will support the presence, participation, self-determination and contribution of persons with an intellectual impairment in their communities;
- to foster the exchange of ideas leading to new ways of thinking about persons with an intellectual impairment.

The Institute conducts, sponsors and publishes research in a wide range of areas, with a major focus on public policy and funding, on studies of innovative social programs and on the development of policy alternatives. It offers training programs and workshops across Canada on topics such as integrated education, post secondary education, leisure, employment, and alternatives to intrusive methods of behaviour modification. Through its Information Services, which include a library, a book and film distribution service, and a computer accessible information system, The Institute provides up-to-date information to the public, professionals and community groups. The Institute also publishes the quarterly magazine **entourage**.

The G. Allan Roeher Institute is sponsored by the Canadian Association for Community Living, a voluntary organization bringing together over 400 local and twelve provincial and territorial associations working on behalf of persons with an intellectual impairment.

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Foreword

For many persons who either have disabilities or who work in this field, it has long been obvious that the community inclusion process faces critical challenges that go beyond the now familiar ones of improved access to services in the community, more enlightened developmental programming, more adequate legal protections, political empowerment, and more equitable distribution of public resources. As critical as those matters may be to the health and well-being of individuals and communities, there are important challenges and barriers that need to be addressed at the level of personal interactions. And experience has shown that these can be extremely difficult to address effectively, with traditional voluntary and community development initiatives offering only partial solutions. For persons with a mental handicap, or with multiple or intensive disabilities, the challenges in this area can be particularly crucial. As one self advocate remarked, "Our lives will always be in ruins, because people don't take the time to be our friends."

Indeed, the now quite widely recognized need to address the personal disconnectedness experienced by many persons with disabilities in our communities is one reason why The G. Allan Roeher Institute undertook *Making Friends: Developing Relationships Between People With Disabilities and Other Members Of The Community*. While there will probably never be a definitive work in this area, *Making Friends* does bring together in one monograph a range of new insights drawn from intensive personal interviews, and of current views from scholarly and other sources. The aim of the research is straightforward: to outline why the development of relationships is an important issue and to trace the implications of inadequate development in this area; to examine some of the key barriers to the development of social networks; and to explore practical options that can be used by those attempting to facilitate relationships in the lives of persons with disabilities. The research looks in the first instance at the situation of persons with a mental handicap. In other instances the research either explores the situation of persons with disabilities more generally, or uses language in such a way as to include persons with a mental handicap in the regular discourse on disability.

Because human relationships do not lend themselves to pat formulas, *Making Friends* does not provide simple techniques. Yet it does offer many principles and insights that can expand how one thinks about human needs, and that can enrich how one goes about attempting to address those needs in terms of planning and concrete support. As such, it has important implications for persons working in most human service sectors involved with disability, as well as for members of the informal social networks of individuals with disabilities.

It should be especially useful to those working in the leisure and recreation field, because there are rich opportunities for expanding individuals' relationships where activities have shared participation and mutual enjoyment as the key aims. Accordingly, *Making Friends* can be usefully read along side *The Pursuit of Leisure* and *Leisure Connections*, The Institute's companion volumes on the present theme. Those who would find the present volume helpful include not only recreationists, however, but family members and others providing supports to social development and leisure in the context of independent living, as well as those facilitating social inclusion in school, workplace, religious, and other community enviroments. A clear implication of *Making Friends* is that greater collaboration by all stakeholders in the well-being of persons with disabilities is required in supporting the development of relationships in the community.

I would like to thank the following people for their invaluable contributions to this book: Peggy Hutchison, who was the principle researcher and author; Marcia Rioux, Wanda Taylor, and Karen Yarmol-Franko from The Institute, who provided strong direction and editorial support throughout the project; and to John Lord, who took time to comment on the draft manuscript. The financial assistance of Fitness and Amateur Sport Canada was essential to the completion of this monograph. Perhaps most important, I would like to thank those listed in Appendix A for contributing their ideas, hopes, and experiences through the interviews. All these efforts have resulted in a book that we hope will provide new insights, that will bring a clarity of focus to those working for the inclusion of persons with disabilities, and that will serve as a catalyst to creative efforts in this important area.

Cameron Crawford
Assistant Director

Introduction

In recent years, many of those concerned with the quality of life of people with disabilities have been coming to an important conclusion: friendships, a key indicator of quality of life, are seriously lacking in the lives of most people we know. This situation seems to exist not only for individuals who are entirely segregated or isolated from their communities, but also for many people who actually live in their communities (Lutfiyya, 1988).

The main focus of the integration and deinstitutionalization movements to date has largely been on integrating people into community settings, so that they live alongside other valued citizens. The emphasis on physical presence seems logical, since presence is a necessary prerequisite to more involved kinds of participation and the development of relationships. Many families, friends, self-advocates, and human service workers, however, now realize that without strong relationships, many individuals become overdependent on services and professionals. They feel isolated and lonely. Volunteers become their main source of companionship. Most important, they continually feel vulnerable to institutionalization (Lord and Hearn, 1987; McKnight, 1987).

In the past few years, a new movement known as the "community movement" has emerged, distinct from earlier integration and community living movements. One emphasis of the community movement has been to help us understand more about barriers to friendship. For example, segregation is seen as a major barrier because it prevents

individuals from meeting a broad range of people, and thus cuts them off from a potential source of close friends. Services, professionals, and even volunteers are seen as another major barrier because they often impose structures and policies that inhibit true friendships from developing and flourishing. The final major barrier is attitudinal: few people believe that valued citizens in our communities are capable of or even interested in developing close friendships with people who are labelled handicapped (Bogdan and Taylor, 1989; McGee et al., 1987; McKnight, 1989).

While these barriers are experienced in a dramatic way by people in our society who have disabilities, it is generally difficult for many of us to develop strong social networks and friendships. Various changes in society, increased transience and mobility in jobs, the growth of big cities, an entrenchment of the work ethic, and increased dependence on professionals, have alienated us from our communities, families, and friends (Gottlieb, 1985). Some people feel that attempting to create opportunities to develop friendships for people who have traditionally been isolated is unrealistic given this alienation. Another more optimistic view, however, is that the community is a hospitable, vibrant place where we rely on each other, care for each other, and tolerate differences.

This view of community is helping us understand its importance and potential for the development of friendship rather than that of services (O'Brien, 1986; O'Connell, 1988). Community, if fully understood, becomes an important vehicle, creating opportunities for people to meet a range of other citizens and encouraging deeper relationships and friendships to emerge. This concept has been discussed thoroughly over the past few years in the literature and at workshops on community and friendship. While some people still think of community as a *place* (for instance, a neighbourhood), it is more often discussed in terms of *people* (social networks, self-help groups, relationships, sharing, cooperation, connections, friendships), or in abstract terms related to a *sense* of community (inclusion, diversity, interdependence, commitment, familiarity, participation, acceptance, equal opportunity).

These new ways of thinking about community, primarily focusing on enhancing quality of life through stronger social networks and friendships, have become a major issue for individuals, families, and services (Perske, 1988). Integration efforts are beginning to focus less on simple presence and more on ways of facilitating friendships, relationships, and community (Bridge et al., 1988). For example, people

concerned about supported work are putting relationship development on a par with other employment issues (Sandys and Leaker, 1987); recent institutional closures are showing that strong networks of family and friends make a difference to quality of life once people are back in the community (Lord and Hearn, 1987); friends are being recognized as an important element of recreation and leisure (Cormier et al., 1986); and school integration is seen as synonymous with strengthening friendships and peer supports (Brown et al., 1989; Forest, 1987).

These are new ways of thinking about people and their lives. It is important that those of us who are concerned about community and friendship have a chance to share what we have learnt with others who are struggling with similar issues. It is for this reason that The G. Allan Roeher Institute initiated a project on friendship, as a way of pulling together the knowledge and learning about friendship that has emerged from numerous groups:

- parents and family members
- friends
- advocates and interested community members
- self advocates and self-help groups
- individuals involved in deinstitutionalization, and integration
- community and friendship projects
- community groups such as YM/YWCAs, churches, and clubs
- professionals and volunteers, such as teachers and recreationists
- employees or employers and residential staff
- researchers

The ideas presented in the upcoming chapters are based on three sources. First, personal stories were gathered from individuals across the country who are currently involved in some aspect of this important issue of friendship. Their stories came mostly from in-depth telephone interviews (see Appendices A and B). Second, an increasing number of people are documenting their experiences in the literature and, in the process, making available a rich and up-to-date source of information about friendship. Third, a growing number of people are conducting research in the area of community and friendship, with qualititative research providing the most insights and depth of information needed

at this time to contribute to our growing knowledge and awareness of friendships and community.

While this book will not provide simple recipes or techniques for making friends, we do hope that it will begin to address some of your concerns and questions about friendship. These might include:

1. Why are friends so important for all people, but especially for those who have a handicap?
2. What are the most significant barriers to people making and keeping friends?
3. How can we begin to overcome these barriers?
4. What should we learn about friendship to be better facilitators of relationships?
5. What can we learn from others who are working in the area of friendships?

Creating opportunities for strong relationships and enhanced quality of life is not an easy task. It requires a concerted effort on everyone's part to change our attitudes, our knowledge of community and friendship, and our approaches to supporting people. But those who are tackling this issue as their first priority know the immeasurable benefits it has for all people; the safeguards needed to ensure that friendship facilitation does not become just another technology applied to people with disabilities; and, most of all, the tremendous capacity of our communities to respond in new ways.

Chapter 1

Friends Are Important

The Blessing of Friendship
A blessed thing it is for any man or woman to have a friend; one human soul whom we can trust utterly; who knows the best and the worst of us, and who loves us in spite of all our faults; who will speak the honest truth to us, while the world flatters us to our face, and laughs at us behind our back; who will give us counsel and reproof in the day of prosperity and self-conceit; but who, again, will comfort and encourage us in the day of difficulty and sorrow, when the world leaves us alone to fight our own battle as we can.

Charles Kingsley

It is logical to wonder why we need to have a whole chapter in this book that addresses such a fundamental question as "why are friends so important?" On the one hand, it is a topic that we hardly need to discuss because everyone knows how important friends are for companionship, love, affection, and support. On the other hand, the vast majority of the population does not consider friendship with people who have a disability a priority or even a possibility (Bogdan and Taylor, 1989; McGee et al., 1987; McKnight, 1989).

An in-depth look in this chapter at the reasons friendships are important for people who are labelled reveals that they are largely the same as for any other citizen. However, additional reasons exist for people who are labelled because of the vulnerabilities associated with

having a disability in our society. For example, friends significantly increase the possibility of a labelled individual living a normal life; friends who are valued can help develop that person's positive reputation; and friends can help monitor services and ensure that living in the community is not jeopardized (Hutchison and McGill, 1990; McKnight, 1987; O'Brien and Lyle, 1986; Rubin, 1986).

Why Are Friends Important?

It is important that we spend time in this chapter talking briefly about each of the reasons friendship is important. If we genuinely understand the value of friendship, we are much more likely to make it a priority in our lives and to stick with it when barriers arise. As you go through this chapter, you will notice an overlap and various connections between many of the questions. This only serves to underline our belief that friendship is needed for all of these reasons, and not just for one or two isolated ones.

Intimacy and Affection

Close friends provide us with the opportunity to fulfill our need for intimacy and affection. We all need at least a few intimate friends to talk with, to be close to, and with whom to share our deepest feelings and thoughts (KWACL, 1987; Lutfiyya, 1988, 1989). When people are denied the opportunity for intimacy and affection over a long period of time, they develop deep feelings of frustration and rejection (Lyons, 1987; White, 1986). Restricting intimacy in a relationship is equivalent to cutting the flow of energy and love that makes the relationship. It stifles and eventually kills it.

The more severe the person's disability, the more vulnerable he or she becomes to others' control over personal needs, and thus the more restricted the opportunities for genuine intimacy and affection. Family and staff will often assume they are the best judge of the person's ability to deal with intimacy, and wish to protect him or her against the hurt and rejection that sometimes follows when friendships do not work out. A common rationale given when parents or staff interfere with or prevent a new friendship is that labelled individuals are less capable of dealing with intimacy in their lives. There is, however, no evidence that a person with a very severe disability lacks the ability to make friends

or has any less need for affection, love, and intimacy than others.

Intimacy grows out of close, long-term relationships with others. However, people need to experience intimacy with friends, not staff. Many human service policies often restrict intimate relationships from developing and flourishing, including those with others who have a disability. If people are forced to rely for intimacy on staff and volunteers, it becomes virtually impossible to achieve the depth of feeling, intimacy, love, and affection we all need.

Feeling Valued

Having close friends can help us feel important and valued (KWACL, 1987). While we do not want to suggest that our feelings of self-worth should be determined by whether we have close friends, there is no denying that friends play an important role in helping us feel more valued. One parent talks about the effect that friends have had on her daughter. "Yvonne's school picture shows how proud and happy she is. Her year book is scrawled with autographs: 'Your friend,' 'Your friend always,' 'Your friend forever'" (Penner and Penner, 1987, p. 35).

Friends make us feel valued because they remember small things that are important to us and that may go unnoticed by others. They recognize our uniqueness and see our differences as strengths. A good friend accepts us for who we are, regardless of any weaknesses. This does not mean that friends are not honest or open when there are things that bother them, but it does mean that our friends do not reject us for these reasons.

We should not only emphasize the importance of having friends, but stress that one should not be restricted to having only or mainly friends with a disability. One of the reasons is that having friends who are valued can help the person develop a more positive reputation in the community (Gold, 1986; O'Brien and Lyle, 1986; Wolfensberger and Thomas, 1983). When the person knows he or she has friends who seem to be valued by others, that makes the person feel valued. Similarly, when others see the labelled person with people who are already integrated into the community, they will tend to see the person in the same light. As well, having friends who have many more contacts, opportunities, and relationships in their lives gives people access to experiences they might not otherwise have and to other people they would not otherwise meet. It is important to note, however, that we are not encouraging people to make friends with others solely for reasons of

reputation. This is simply one of many subtle reasons friends are important.

Companionship

Friends provide the companionship we need when we want to be with others. While some people like to do things alone much of the time, most prefer companionship when doing things out in the community. This parent's comment reflects the importance of friends for companionship.

> Joe is outgoing and likes to be busy. He needs friends to do things with. He is very sports minded – he knows a lot about hockey, reads sports magazines, and studies hockey and football. He has many things in common with Ron, his friend. (June Kaube)

We also need a range of friends so that we have a choice of people to be with at any one particular time, depending on our moods or interests. Sharing a common interest is one of the significant ways people develop and maintain friendships. We tend to have different friends for different interests or areas of our lives (Rubin, 1986). Friends do not want to feel pressured to do something with us that they are really not all that interested in simply because there is no one else to do it with. Similarly, we should not be restricted from doing something simply because we have no friends with that interest. When we have several friends to call on, it allows us to have more spontaneity in our lives, whereas if a person has only one friend, a lot of organization is necessary to ensure that both people are available at the same time.

> Her friends Robin and Heather, who live nearby, are good friends, but it's not enough. If one's busy, that just leaves one alternative. Everyone needs lots of friends, so they can learn the skills needed to select friends. If she had more friends, she would be able to be more actively involved in selection. (Linda Till)

The aspect of choice emphasized by this parent is especially important for adults who need a range of friends to choose from for long-

term companionship, be they roommates or spouses. While some people may prefer to live alone, this should be a personal choice, not a decision made for lack of other options. Many people with disabilities tend to end up living with someone they don't know, usually another person with a disability. But living with someone whom the person knows and trusts will more likely contribute to a successful living arrangement. Marriage and long-term intimate relationships become more possible and desirable when a person has a range of close friends. As well, friends can provide the support all couples need to have a meaningful lasting relationship or marriage.

Taking Risks

Having friends often gives us the confidence we need to try new things and take risks in life. When we are cautious to try something new, friends provide encouragement. They even go one step further to reassure us that support, whether from themselves or others, will be there if we need it.

When people don't trust themselves to make decisions or to try new things because of previous experiences or lack of opportunity, it is important that at the beginning they at least trust those who are encouraging them. Over time, this kind of assurance, support, and caring helps the person develop his or her own sense of security. The delicate relationship between confidence and trust is reflected in this statement by a friend.

> She was very shy at the beginning; but now as time goes on and she trusts me, she has opened up. I am outgoing. She discovered she could be herself and not fear that someone would put her down. She says she is happy now. I don't like to take credit for her coming out of herself. Sharing my everyday life with her might have helped. But she did it herself. (Linda Morgan)

As well, parents or residential staff sometimes feel more secure and will allow more freedom to a person with non-labelled friends than when alone or with other people who have been labelled. The person may be able to stay out later or participate in activities that might appear to involve more risk. In this sense, friendships with people who have a variety of contacts and resources provide greater opportunities

for the person needing support. For example, having a friend with a car enables more flexibility and greater use of community resources.

Another way that friends are able to encourage confidence is by providing positive role models. People of all ages use their peers as models to learn what is expected of them. Friends in childhood help a child explore the world, discover what is available, and develop the skills that are needed to participate in the community. Friendships in childhood are important for the development of friendships in adulthood because we learn much about social living and relating with others through play and games (Gold, 1986; Gottman et al., 1975).

During adolescence, teenagers need models as they struggle to learn and accept new adult roles and to part with childhood ways. The more someone cares for and respects a friend, the more influence the friend will have on the person. In adulthood, our friends sometimes take on the role of mentor – someone we admire and respect for their support, guidance, and teaching. Individuals often credit people they call their mentors with contributing significantly to their awareness, self-confidence, and personal empowerment (Centre for Research and Education in Human Services, 1990).

Breaking Away From Services

Friends make it possible for us to rely less on services and family. If we have weak social networks and few friends, there is often very little choice but to rely on formal services and/or family for almost all of our needs. On the other hand, when we have a strong network of friends, they can provide many of the things services currently provide, but in a more informal and personal way (Gottlieb, 1985; O'Connell, 1988).

When a service provides support, it is referred to as counselling, vacation support, parent relief, skills training, etc. When a friend provides similar support, we simply think of it as listening, giving advice, going on holiday together, staying over while the folks are away, figuring out together what has to be done to get a decent meal. This does not mean that services are not needed, but that they are needed to a lesser degree if a person has several good friends. As Perske writes, "Friends help us move beyond human service goals. Friends provide us with myriads of options that could never be programmed" (1988, p.2). Friends can help and support us to make our own decisions and to direct our own life (White, 1986). This idea was originally thought of in terms of independence. Many human services continue to have the goal

of independence as a cornerstone of their programs and services. More recently, however, with the focus on community and friendships, it has been realized that promoting independence for anyone, let alone people with limited experience and skills, can be misleading and may lead to extreme individualism.

More than independence, the idea of interdependence captures the concept of friendship within community. It implies relying on others for support and caring, with an emphasis on friendship and a strong social network (McKnight, 1989). While the parent in the following quote draws on the earlier concept of independence, her statement reflects an important and positive reliance on friends, as well as the delicate balance between independence and interdependence.

> Joe's friends help him to have other interests and other friends and to broaden his horizons. He is getting very independent; he knows what he wants and doesn't want. For example, he knows the workshop is a training centre and he gets bored there. (June Kaube)

Support and Advocacy

Closely related to the notion of interdependence is the idea that we all need friends who are available and willing to provide support and advocacy when necessary. Sometimes it is with the everyday issues and struggles that friends can help out. For example, we need to know that we have friends who will listen to us in times of need. Sometimes listening is all that is needed. Other times, the friend may have to provide ongoing informal support, such as driving us somewhere when the car breaks down, helping us understand a legal notice we received, or helping us sort through problems in a relationship (Lutfiyya, 1989).

Parents and others often talk about the important role their children's friends play in communicating issues and talking about aspects of their child's life with which they are less familiar. For example, friends will let parents know about trends and activities at school that the child may not communicate; if a message must be sent for the child, friends can be counted on to pass it on; if the child is not feeling well, a friend will often notice subtle differences before others do; and if there is a problem -- for example, the child is being teased -- the friend can be counted on to defend him or her and speak to the parent or teacher if necessary. A parent and an educational consultant

share these stories.

> One of the kids told me I was sending Doug barfy green salads for lunch, which makes him different; and he doesn't have acid wash jeans. (Margie Brown)

> Wendy's friend can help to provide insights into what's happening in class. She said Wendy's not doing a lot in French but is doing fine in math. This helps us out. (Julie Stone)

Friends can also be counted on when more serious crises arise in the person's life that require advocacy. Sometimes the person's life or well-being is seriously threatened because of illness or lack of safety (Lyons, 1987; 1989). Other times, an urgent legal problem or difficulty in a relationship can create an immense crisis that the person has trouble sorting out alone. Good friends will be needed to provide intensive support, caring, and advocacy to ensure the person comes through the crisis. Friends can give the person the confidence to fight battles otherwise seen as insurmountable by legitimizing the person's feelings. They not only provide the confidence, but the person-power to fight daily battles that often wear the person or family out (Forest and Snow, 1983).

Now and then, a person's humanity and quality of life are threatened. Loss of an essential service, rapid deterioration in a person's condition, death of a parent, or an instance of social injustice can all leave the person vulnerable to institutionalization or other crises that would seriously affect the person's quality of life. For example, when a person has a strong network of friends and support, parents have more confidence that, when they are gone, there will be people who are strongly committed to their son or daughter, to stand by them, and make sure things are alright (KWACL, 1987). Friends who have no conflict of interest and are willing to fight the battle "as if it were their own" are needed as protection from all these vulnerabilities.

As a word of caution, however, it is important that the joyful, caring, happy moments in a friendship be the dominant part of a relationship wherever possible. If the friend is forced to spend most of the time being an advocate, rather than simply being a friend, the relationship runs the risk of being stressed. What this means for individuals who have severe needs or are constantly at risk is that a strong support network and a range of friends are needed, so that

support and advocacy can be shared. It also means that the person and friends need to determine more carefully what supports could logically be provided by services and what needs are most appropriately met by friends. Finding this delicate balance is important for sustaining long-term relationships. One friend, in her own mind, has dealt with this dilemma by separating out her friendship and advocacy functions.

> Sometimes I can go beyond my friendship role and act as an advocate. She had a problem once and came to me with her mom. I was pleased I was able to help her out in this situation. (Linda Morgan)

An interesting analysis from an advocate helps us understand even further this connection between advocacy and friendship. The Rights Now Project is sponsored by the British Columbia Association for Community Living (formerly BCMHP) and was an outgrowth of the People First self-help movement in British Columbia. Their project has taught us that we can't place things like advocacy and rights ahead of or apart from the important issue of friendship.

> Originally we saw Rights Now more as a vehicle for self advocacy and empowering people to be part of social change. But we found people's lives meant nothing without friends. Friends ensure that rights are recognized. We had it backwards. We were emphasizing rights and responsibilities instead of promoting rights through the vehicle of friendship. Rights are not ensured by legislation or by me saying how important they are, but more by the personal supports I have in my life. We have learned that friends are critical. (Kim Lister)

Most important, many people now believe that friends are really the only true form of protection and advocacy and that we can no longer promote approaches to service or support that isolate people from opportunities to make real friends (McKnight, 1989; O'Brien, 1987).

Greater Chance of a Normal Life

With friends, roommates, or neighbours, there is the possibility of living an active, normal life and having a place in the community -- a

life with dignity, security, and fun, surrounded by friends (Kappel and Wetherow, 1986; Strully and Strully, 1985). A normal life in the community implies many things, including a balance of happiness and challenge, contributing and receiving, and friends and services.

Since friends increase opportunities for support, companionship, participation, interdependence, and other things, the chances of a person with a disability living a normal life are greatly increased. This quote from an advocate illustrates the simple things people think of when they talk about having a normal life: "The co-op provides an opportunity for Arnold to live a normal life in his own home with freedom, with his own friends. He can go to the fridge when he wants to or take a bath by himself, not a communal bath. He is not pressured by routines" (Kappel and Wetherow, 1986, p. 38).

Friendship Teaches People Acceptance

There seemed to be no better place to end this chapter on reasons friends are important than the observation that friendships help people who do not have disabilities learn about acceptance (Bogdan & Taylor, 1989; Forest, 1989; Perske, 1988). On the one hand, it is gradually being recognized that people with disabilities can help soften a hardened world (Lusthaus, 1986). When a person gets to know someone very well, as friends do, each develops an acceptance that is based on the other person's strengths and abilities. A person's label and disability take on less importance over time and any differences seem to melt away. In one sense, people with disabilities are actually being seen as teachers of higher order principles, such as tolerance, acceptance, trust, and understanding (Jeff Strully).

When people who are labelled are segregated from the community, those in the community are also cut off from the people who are labelled and all that they have to give. Through their difference, people with disabilities help us to become more tolerant and accepting, challenge society's norms, and teach us the value of compassion and cooperation. Friendships that start at school, work, or in the community provide us with the opportunity to know a diversity of people and to learn to build more cooperative relationships. For example, neighbours have learned that people with disabilities can be good neighbours, friends, and community members. Neighbourhoods where there is a group home or where a labelled person lives can be drawn closer together with the

right kinds of supports (Lusthaus, 1986; Perske, 1980). Schools where one or more children are integrated can help to teach the students values such as support, sharing, and friendship (Forest, 1987). Places of work that include a worker with a disability learn the value of cooperation rather than focusing on more individualistic and competitive attitudes that often prevale in work settings.

It is impossible to develop these sorts of contacts, however, as long as there is an attitude of segregation in our society. For people to be understood and accepted, they have to be known for who they are, and not seen through the lens of assumptions and myths about disability that are unfounded and continue to haunt our society. As we personally learn more about and accept people with disabilities, the task of educating others about the importance of friendships will become easier. For anyone who knows a person with a disability well also knows the person needs friends, like everyone else, and the reasons are not all that dissimilar.

Geraldine Gertz's Story

I live by myself in an apartment in Manitoba. My best friend is Rebecca. We met a long time ago when they put me in an institution because I wouldn't tell [the group home staff] where I was all the time. I don't want to talk about it because it upsets me. But you get locked in there. When Rebecca was phoning me at the institution, the staff was listening in. Anything you do bad at the group home, they say they're going to send you to the institution. They give you pills but I try not to swallow them. The staff make you go to bed early.

Rebecca was my advocate from the Advocate Office. She got me out and took me to live with her and James for six months until I moved to the Co-op. What are friends for? It didn't work out at the Co-op so I moved again and now I'm moving to a new place because the government says my old place is too much and they won't pay for it.

I work part time cutting papers in a government office, but my eyes are going weird so I'm looking for a new job; Rebecca is a school teacher. Now she has moved to Toronto with her husband because he had to build buildings. We write though and keep in touch. I really miss her. Rebecca and I, we're plain old good friends. We're good friends because we write.

When she was here we went out for supper, to the movies, to Rebecca's mom's place and swimming. Next year I am going to fly on an airplane and see her. I know how to fly because I did it before. We went and had our picture taken like the olden days and I have one of her and she has one of me. I like that because it reminds me of her.

She helped me meet Donna, another friend. We're going to go out in the summer. She lives further. My girlfriend Donna looks after two stores. Now Donna is my friend.

Victor Fenton's Story

I'm from Dartmouth, Nova Scotia. I am busy with a lot of things. I was on the CACL Board of Directors and I took trips to Toronto. I like to travel very much. I'm a cub leader and am working on a badge to learn more about children and how to be a good leader. This is through church. I do a lot of public speaking and volunteer work in the movement.

But in particular I work on my hobby, which is model railway trains. I do this with my best friend James. We met through church five years ago. James is older than me and he works with the search and rescue; someday I want to go with him.

James takes me to work with him; we have "man talks," do things out in the community, and go for lunches. We go out and drive the jeep. James is a train buff too. We talk trains a lot and work on our model trains. He loves trains as much as I do. We do a newsletter on our trains together.

James is fantastic; he's the type of guy who understands. We are very close; he's my best man when I get married; he's helped me in my life a lot. I have met some of James's friends, although not very many. I don't know what I'd do without him. We do a lot together and count on each other.

Chapter 2

Obstacles to Friendship

> Our lives will always be in ruins, because people don't take the time to be our friends. Instead they make decisions that will segregate us, congregate us, and put us in places where our lives can become completely vulnerable. We can't live that way and you shouldn't expect us to live that way.
>
> *Pat Worth, 1988*

If friendships are so important, why is it so difficult for people with disabilities to develop and maintain friendships? As Pat Worth notes, the obstacles are significant. We need to understand how these obstacles operate, so we can work to remove them. In this chapter, several important issues will be raised. Some of these ideas are not new. For many, barriers to friendship are similar to the problems experienced with integration, deinstitutionalization, and community living. However, an effort will be made to frame the issues in the context of friendship.

While there are several important barriers or obstacles to be discussed here, it seems that they fall into three broad categories.

1. Low expectations for friendships to develop.
2. Few opportunities for friendships to be initiated.
3. Inadequate supports for friendships to be fostered.

The order presented above is a logical one: when expectations are low, there are few opportunities for friendships to be initiated, and

when opportunities are few, few attempts are made by families, advocates, or professionals to provide the supports that are necessary to encourage and maintain relationships. Understanding these barriers will enable us give greater priority to helping people develop and maintain their friendships (Tyne, 1988).

Misperceptions

At the end of the first chapter, we spoke briefly about one important aspect of friendship: its potential to teach people about acceptance. Unfortunately, in the field of developmental disabilities, and even in the mental health field, the "sociology of acceptance" has been overshadowed by the "sociology of deviance." Specialists in psychology, education, rehabilitation, and even recreation have tended to focus on how people are perceived as deviant rather than on how people who are labelled can come to be accepted by others (Bogdan and Taylor, 1987; Taylor and Bogdan, 1989).

This "sociology of deviance" has been perpetuated in services and society by historical attitudes towards people with developmental handicaps. The stereotypical perceptions of the "eternal child" and a "menace to others" have contributed to much of the overprotection and segregation that still predominate today. These negative perceptions were clearly based on the assumption that people's disability and deficits were the most important aspect of their lives (Wolfensberger and Thomas, 1983). The normalization and rights movements of the 1960s and 1970s helped to begin dispelling these myths and to focus more on the positive attributes of people.

Traditional role perceptions of people with disabilities are therefore at the root of many of our attitudinal barriers to friendships. They helped to create two principal obstacles that we will explore in this section: first, the belief that people with disabilities are not capable (cannot understand the meaning) of being a friend, particularly with people who do not have disabilities; and second, the assumption that non-labelled citizens are not capable of or should not be interested in developing friendships with people who have disabilities.

Is Everyone Capable of Friendship?

Everyone is capable of friendship and friendship is possible between all

kinds of people, regardless of their interests, ethnic background, age, sex, or disability. But one of the major obstacles to friendship, especially for people with a developmental disability, is the belief that they are not capable of being friends with other citizens in the community (O'Connell, 1988). This is based on the assumption that things such as good communication, cognitive development, reciprocity, and similar life situations and experiences are all essential prerequisites to friendship (McGee et al., 1987). Since this is such an important barrier to friendship, we have devoted the next chapter entirely to discussing the ingredients of friendship, in the hope it will help diffuse this myth and offer practical suggestions for building new relationships.

When there is little or no expectation for people with disabilities to have friends, a range of other priorities are permitted to dominate the person's life. Life skills development, speech therapy, work training, and even recreation therapy are all examples of programs where the focus on the person's deficit is pre-eminent. Friendship is seen as a frill or an after-thought rather than as something fundamentally crucial to the person's well-being and quality of life (Centre for Research and Education in Human Services, 1990a).

While many people may not appear to have the ability to be a friend, it is more accurate to say that they have not been given the opportunity to learn how to be a friend. The following quote from a parent illustrates this concern:

> Many people have not had the chance to learn the expectations and social obligations involved in friendship. If you're not expected or given the opportunity to interact and learn the rules of the game, you'll have trouble making or keeping friendships going. (Linda Till)

Are Communities Interested in People Who Are Labelled?

The second major obstacle to friendship development is the belief that friendships between ordinary citizens and people who have disabilities are not possible. Again this is simply not true. However, the specialized approach to serving people with disabilities indicates that professionals themselves believe that ordinary citizens are not capable of or willing to provide basic supports required by most people with disabilities, including all the dynamics of being a close friend. For years those in the community have watched professionals in the field of disability

segregate people who are labelled in special facilities for rehabilitation, design separate education programs, rely on therapists, specialists, and other professionals for every possible aspect of the person's life (Taylor, 1988). Is it any wonder that the ordinary citizen would consider him or herself not qualified enough to be involved in the basic aspects of the person's life? Tragically, segregation "reinforces the belief that some people are so different they cannot fit in or successfully contribute to their society. Typical community members lose the chance to meet, get to know, and be with individuals with disabilities" (Lutfiyya, 1988, p. 5).

We are just beginning to learn the extent to which people in the community are willing and able to become deeply involved in the lives of people with disabilities (Perske, 1980; Taylor and Bogdan, 1989). Much of the recent documentation on friendship shows that people are extremely capable of accepting one another, despite differences and disabilities. It shows that a person's need for support in the area of health and safety does not automatically preclude friendship and that many people have not been involved simply because they have not been invited (O'Connell, 1988). The following quote from an advocate and facilitator of friendships illustrates both major barriers discussed in this section.

> This generation finds it difficult to invite others into their lives; it's almost like the work ethic. To be aggressive, especially in the area of friendships, is foreign. We've realized it's not just the parents who don't believe it's possible [for a person who is labelled] to make friends. But it is those surrounding the people as well. We need continually to ask ourselves: "What barriers are we putting in front of this person to making friends?" We have to learn how to invite people into our lives and the lives of others. We have to learn how to get beyond being an acquaintance and be willing to ask and share. (Cathie Duchesne)

A belief that friendships are possible between people, particularly someone who has a mental disability and someone who doesn't, needs to be grounded in a "sociology of acceptance." "Accepting relationships is not based on a denial of the disability or difference, but rather on the absence of impugning the disabled person's moral character because of the disability" (Taylor and Bogdan, 1989, p. 27). Lutfiyya's (1989)

recent research reinforced this concept when she found that disability played a role in the friendship pairs she studied. The disability was not denied but accepted and accommodated. The "sociology of acceptance" is important to overcoming our low expectations, so that we can encourage rather than prevent badly needed friendships, and therefore a good quality of life, for people with disabilities. Seeing communities as potentially accepting is an important motivation for beginning to create communities that are responsive, hospitable, and responsible (Lord, 1985; O'Connell, 1988).

Few Opportunities to Develop Friends

When our expectations of people are low, we deny them certain opportunities that are necessary for friendships to begin and flourish. The two major barriers that seem to limit friendships are: first, people tend not to have access to or find themselves in the kinds of environments in which they might meet potential friends; second, the structure of the majority of the programs and services in which many people with disabilities spend their time inhibits friendship (Lutfiyya, 1988).

Being in the Wrong Place

O'Brien and Lyle (1986) explain that there are five conditions needed to significantly improve the quality of life for people with disabilities: the opportunity to share places, to make choices, to have dignity and a positive reputation, to grow in relationships, and to develop. The first condition, sharing places, means having access and the opportunity to go to the same places that valued or ordinary citizens go. This is an essential condition for friendship, since without contact there is no possibility to get to know other people and eventually develop relationships (Brown et al., 1989; Galati, 1986; Gordon, 1987; Pivato and Chomicki, 1986; Strully and Bartholomew-Lorimar, 1988).

> Being in the university has been good because she's not segregated as before. Now she has 28,000 possibilities for relationships. Imagine how that opens up a whole new set of doors. (Sonja Clark)

Since large numbers of people with disabilities are still segregated in

many or all aspects of their lives, it is virtually impossible for them to connect with a range of people who could potentially be friends and have diversity in their relationships (Lutfiyya, 1988, 1989). A parent's frustration when her child can't share places with her friends is illustrated in this quote.

> Brandy goes to a different school than other kids, so that doesn't help. Her two best friends here have gone off to French immersion. She is Catholic but the catholic school had a developmental class in the basement with no elevator and too many stairs. How could I send her there? (Diana Rees)

Wolfensberger and Thomas (1983) also help us understand the importance of being in the same places as others. They talk about social roles that valued citizens have, such as being a spouse, neighbour, colleague, parent, volunteer, and explain that it is in these roles that people have the chance to meet a range of other people. When, however, a person's primary role is that of client, he or she is usually restricted to segregated settings and is thus unable to meet anyone other than professionals, volunteers, and others who have been labelled. In this sense, "clienthood" is a major barrier to meeting and making friends with people who are valued (Lutfiyya, 1988); to being seen as capable of contributing to society (Lusthaus, 1986); and to creating a positive image or identity (McGill, 1987). This recreationist has had the opportunity to talk with people who have experienced segregation and isolation.

> A lot of adults were saying they had been segregated in school and recreation and hadn't had the opportunity to make friends, except with other disabled people. They also didn't have the opportunity to get together with friends, even if they had them. If a person has friends with a car, it's no problem to be able to go places; but people don't do things naturally because they don't have friends. (Judith Armstrong)

The assumption, often unconscious, is that the person's disability is the common denominator that will provide the basis of a friendship. While this may sometimes be true, the sociology of acceptance is teaching us that it need not be so and in fact is usually not enough. This

explains why so many people have so few friends from their segregated settings, despite having spent years together. Pat Worth (1988) helps us understand the anguish experienced by so many people who have been segregated and prevented from sharing places.

> I go into some of the institutions in Ontario and I look at the faces of the residents and I see the signs of giving up, the signs of being afraid, the signs of not knowing what is out there because all you know is what is there. They don't have true friends, they have each other, but what they have is people who are caught up in the same circumstances, who are very vulnerable to the system.

How Are Services an Obstacle to Friendship?

John McKnight (1987) believes that services themselves present one of the greatest barriers to friendship. He describes the pyramidal and hierarchical structure of service mechanisms, allowing a few individuals control over many. The result, he explains, is that services are incompatible with the idea of people acting together through mutual consent, an important aspect of friendship. Lutfiyya (1988) also believes that human services interfere with friendship development, since continuity in relationships is almost impossible in situations where there is high staff turn-over and burn-out. This is aggravated by the reliance on a tiered system of service delivery and the concept of least restrictive environment that require individuals to move from environment to environment (Taylor, 1988).

McKnight emphasizes that human services cannot and should not play an important role in promoting friendships. He says human services should allow relationships to happen, but not actually take on the important role of facilitating them, for fear of perpetuating control in an area that should not be controlled (McKnight, 1987; Strathroy and Area Association for Community Living, 1987). The following comment shows how one person is aware of the importance of staff allowing relationships to happen.

> Staff are encouraged to get the door open and then step back, not worrying about taking credit. Helping staff to understand how they can make or break relationships is important. Staff must know that they can set up barriers to

> friendship. We must teach facilitators and paid workers to allow relationships to come in. You have to work at it. There are no recipe books. (Leslie McAneeley)

It is now being recognized that too much focus has been put on integration into formal programs, particularly in recreation, with the measure of success being on numbers of people integrated rather than the opportunities for building relationships that carry over to other areas of the person's life. Many people interviewed feel that formal programs seldom lead to friendships and that carry-over of friendships into other settings is difficult.

> Derek's relationships don't extend from school into other areas of his life. Kids don't phone him because his phone skills are so poor, whereas this is the way other kids really communicate with each other. So they have to come over and that makes them think twice. We tried putting him in recreation programs, but those don't mean a thing in terms of friendships. Kids come from all over the city and it never leads to anything. The most important thing is where a kid goes to school. You're wasting your time if you haven't got them integrated in the neighbourhood school. (Margie Brown)

Similarly, teachers' attitudes are still very much a problem affecting opportunities for children in schools -- not just their attitude towards children with differences, but their attitude toward educational practices. This parent shows how formal services still know very little about this idea of friendship.

> Teachers are still a problem. They are so traditional; if they see a relationship starting up and the two are giggling and having a good time, their typical response is to split them up. We are trying instead to help them see that this is a good starting point both for a friendship and for learning. (Margie Brown)

The short time frame of most programs offered by recreation agencies limits chances for people to see each other often and over an extended period of time. In addition, constant supervision creates a

barrier to the development of close friendships. Because many people regularly have most aspects of their lives supervised and programmed, they lack opportunities or time for spontaneous leisure with friends. Participation in ongoing clubs is generally infrequent, while drop-in programs, such as fitness activities, have a large turn-over of participants inhibiting easy socialization. While other activities, such as camping or spending a day at the beach, are available and appropriate, they provide limited potential for developing friendships (Sandys and Stafford, 1987).

Many of the available integrated settings are also highly competitive (McGill, 1987). In these settings, an individual's disability is often highlighted, making the person feel uncomfortable or excluded for certain aspects of the activity. Social experiences are often sacrificed for emphasis on performance. And winning becomes the primary goal of the activity. In a society that is generally based on the Darwinian principle of survival of the fittest, competitive programs present an enormous barrier to integration.

Many people simply don't have money to join clubs and organizations that others join to meet friends, or to take holidays independent of human services (Sandys and Stafford, 1987). While money should not be important or necessary for friendship, the reality is that if individuals are going to "share places" as a way of meeting and connecting with new people, it must be recognized that the costs associated with many places are prohibitive for individuals on pensions or low-income jobs.

This comment from a recreationist, however, indicates optimism that formal recreation programs have potential for friendship, especially if made a priority.

> It's true that many people with disabilities have been programmed to death. But most of us take part in some formal recreation activities and there are people from those walks of life that I'm still connected to. The potential is there. At the beginning we used to recruit volunteers, but we found that's a real hindrance. We now try to find ways of drawing people in to have a mutual experience. We say "what we're looking for is people who want to get involved with other people." Many of them are still friends. I don't think you can be too hung up on semantics. (Judith Armstrong)

Role Confusion

Judith Snow explains that there is a big difference between "being a friend" and "being friendly" (Community Network for Education and Training, 1987). As stated earlier, human services should help relationships to happen but not actually provide them, since this would confuse the roles of a friend and a staff person or support person. If a staff person who is friendly assumes he or she is meeting the friendship needs of a client, little effort to facilitate other friendships may be made. Having a lot of people in our lives who are "friendly" is not enough. Thus, spending time understanding the kinds of friendship a person needs goes a long way towards overcoming the first major stumbling block – failure to understand the meaning of friendship itself.

How human services are run is particularly important for people who are returning to the community after long periods of segregation and who have no links to family or community. Staff can play a vital role in facilitating friendship as long as they do not perpetuate a situation that ultimately prevents the development of friendship. "Human service workers cannot program friendships. They can, however, set up frameworks in which they can happen" (Perske, 1988, p. 2). Staff can also link individuals up with those who are in a position to facilitate the development of relationships. This aspect will be further discussed in Chapter 4.

Conversely, friends must also recognize that there is a potential source of conflict between a person's role as a support person and as a friend. This may need to be discussed or clarified between friends, particularly if one person is playing a very strong support role (White, 1986). It is important that nothing comes between friends, since staff support may be available from other sources. Friendships can be jeopardized if the potential conflict between the role of friend and support person is not dealt with and resolved.

Inadequate Supports

The final major obstacle to friendship development discussed in this chapter is the lack of adequate supports for friendships to be fostered (Lutfiyya, 1988). There are several reasons why these supports are not made available.

Interfering in a Natural Process

There are many people who feel that friendship is a natural phenomenon that should not be tampered with or facilitated. They believe that friendship is a very personal issue, often involving a natural attraction and bond between people. If others begin to tamper with this process, they run the risk of creating artificial relationships, which, in the long run, will not be lasting.

> Helping someone to meet people and make friends can be difficult. Formal, programmatic efforts to do so contradict our society's notion of how relationships are formed ... Arranged introductions seem an artificial and heavy-handed way to establish relationships. (Lutfiyya, 1988, p. 8)

While it is important to let friendship develop naturally, the belief that it should not be encouraged or facilitated has unfortunate consequences for individuals who lack the skills to make friends and the conditions to meet people. The simple reality is that many individuals are unable to have friends without some kind of support (Gordon, 1987). Friendship is important enough for us to risk the effects of contrived relationships, in the hope that these will lead to long-term bonds between people (Smith, 1987). Emma Pivato's research, for example, has shown that some structure is needed with children at school for friendships to evolve.

> We found the need at recess to provide some sort of deliberate structure, like having another child be a buddy and having a plan that the two would do. Without some structure, children were found to be isolated. There also needed to be a deliberate attempt to find ways that children can interact with each other. For example, with my daughter we found a device that would allow her to do a form of wheelchair bowling, tiddle winks on her tray, and wheel chair races at school (which the board stopped because of liability). The most important lesson we have from the research is that you cannot assume friendship is going to happen. (Emma Pivato)

Some people's experience, however, has been that more formal approaches do not always work. They understand that some kind of

facilitation and support is needed, but they feel it should occur as naturally as possible so as to preserve the voluntary and self chosen nature of friendship (Lutfiyya, 1989). These comments from a human service worker and from two teachers reflect their concerns about more formal approaches.

> Trying to match a person can be devastating. We tried introducing one man to more than forty people. What we found was that a more natural situation worked better. He joined Overeaters Anonymous where he had the opportunity to meet a number of people, and friendships happened more naturally. (Jamie Hicks)

> We try not to centre [isolate] the kids out so much – just involve them in the activities of the class. We let friendships grow naturally. We read a story to the class on friendship; if the kids start playing, we encourage it. (Cheryl Elliott and Jenn George)

Is Friendship a Basic Need?

At the beginning of this chapter, we discussed how, when there is little expectation for an individual to make friends, a range of other priorities are permitted to dominate the person's life. This discussion needs to be extended one step further. It is also easy for those facilitating friendships to resort to providing basic needs when an individual's basic housing, nutritional, medical, or financial needs are not being met. This has been the experience of even those who have made facilitation of friendship needs their top priority. They have found it difficult to think about providing friendship supports until at least these other basic needs have been attended to.

Those responsible for facilitating friendships often turn as well to providing more basic needs rather than friendship when they experience difficulties in providing the supports necessary for friendship to develop.

> It would be easy to stop at finding a place to live, a dentist, a doctor, and work. If we instead judge successful community living by counting the number of relationships in a person's life, we have to do a lot more. The statistics tell us typical

> people have between one hundred and two hundred such relationships and contacts. The average person I work with has zero or one coming out of the institution. So part of my tremendous responsibility is to lay the groundwork or spirit for recognizing the importance of relationships in our lives (Leslie McAneeley).

The difficulty here is that, if only at a subconscious level, friendship is seen to be less crucial than other material needs, whereas it is also essential to one's quality of life (Centre for Research and Education in Human Services,1990a). Lutfiyya (1990) found that it was absolutely critical to provide extra support for friendships during certain critical life events to ensure the relationships continue.

The emphasis on making the development of friendship a priority should not imply isolating it from the rest of the person's life. We need to try to keep the whole person in perspective when thinking about friendship development.

> Here's what I think the focus should be. We need to look at the whole life of the person: their family, their associations, other opportunities, and their friends. If we just focus on one and judge the quality of their life, we are too narrow; we miss some things. It's the whole thing that makes the person have an enriching life and experience. (Jeff Strully)

Does the Person Have a Say?

The very nature of friendship development necessitates the full participation of the person who requires support. The dilemma we have is that very few people, including families, advocates, and human services, are effective at involving people in a full and genuine way in important life decisons (Rights Now, 1990; Worth, 1988). People with disabilities are still very much under the control of others and much of the involvement that does occur tends to be at the level of consultation. This is why the self-help movements, People First, for example, focus their efforts on teaching people their rights and engaging people in the struggle and process of empowerment. This parent understands the important ramifications for the future when people can fully participate and become empowered.

> All the stuff we're doing is for more than friendships now. In the future we want Becky to be able to participate directly in whatever occurs in her life. This includes deciding what to wear, where to work, who to live with, and who she wants to care for her. If she doesn't build a sense of how to participate in her world now, let alone take some control, then there won't be any hope that she will be able to manage this in the future. (Linda Till)

However, as long as people are not empowered and in control of their lives, any efforts at facilitating friendship run the risk of being controlled and contrived by others. We have already seen this happen in so many other areas of people's lives. Involving the person in the whole process of friendship ensures that the individual's needs, interests, and preferences will be respected. Friendship is of such a personal nature that the individual must be able to choose who will be his or her friends, decide when to get together, and assess the suitability of the relationship (White, 1986). Sometimes, involving the person may seem difficult because of the person's lack of experience or difficulty in communicating. But not unlike communication, there are very subtle ways of knowing a person's wishes and having them be involved in decisions regarding their own life. The same parent who talked about full participation above has noticed some very important subtleties.

> Tracy is a friend of Becky's from the nursing home. We did not realize they were friends when Becky was there, even though they were roommates. After coming home, Becky had nightmares about the place after every sighting of a person connected to the nursing home, or even mention of any familiar names from her time there. But we did notice that if we talked about Tracy, she wasn't disturbed. This made us realize that there was something more between them. So we gave them the chance to get together. We're really glad now that we were able to rescue that friendship; it's really important to them. (Linda Till)

Almost as important as involving the person as a full participant in decision making is the value of soliciting the input of peers or friends. Often friends have insights that others cannot possibly have, and if asked, can provide information that can not only assist in the facilita-

tion process, but enhance the quality of the person's life. In some schools, for example, teachers and parents are attempting to increase the involvement and say in decisions, not only of children with a disability, but also of their peers (Ruttimann and Forest, 1986).

> We have relied on other children to tell us what the kids can handle, and that gives them responsibility for decision making. Every Monday the circle meets for one kid and we work through the problems -- everything can be discussed because it's on the table. (Cheryl Elliott and Jenn George)

Barriers Are Not Insurmountable

While it is very easy to get discouraged by the immensity of the problems or obstacles, it is also possible to see that many concrete things can be done to raise low expectations so friendships can develop, create new opportunities for people to meet a range of ordinary citizens in the community, and provide the kinds of supports that are necessary for friendships to be fostered.

People who have been working on developing supports and tackling different approaches find that the barriers are real, but they are not insurmountable. Like many other areas that are being addressed, the largest barrier is often the lack of acknowledgement that the issue is important and possible. Once people commit themselves to doing something, the mechanisms, approaches, or alternative ways of doing it seem to be more plentiful. Fear of failing should not be the reason that something important is not tried. Acknowledging the obstacles and tackling them one by one is an important part of the process of expanding opportunities for people to have more friends and stronger relationships in their lives.

John Nevard's Story

When I was a kid, I never went anywhere. My brothers never took me anywhere, so it was hard for me to have any friends. When I was eleven, my parents put me in an institution. They thought I was mentally retarded because I have cerebral palsy. I lived there for three years, an experience that later motivated me to write my life story, which I would like to have published.

I remember going through puberty was especially hard. I was put through hell because my parents figured I'd never get the chance to have real relationships, especially with girls, so they didn't bother helping me understand.

I started making my own friends with people who don't have a disability when I stopped being sheltered. But there are very few people who are close to me, even now, because I don't let people get close to me. I can spot when someone is sincere or not. It's experience that helps you be able to tell. But many people with a disability have not had the experience. They get taken advantage of because they have not been trained to survive in the community. It's those of us who have experienced barriers making friends and living in the community that are in the best position to tell others about this. That's why I worry about staff teaching people, because they haven't had the experience.

I'm doing not too badly with friends now, but what I find really frustrating are the limitations put on me around women. I asked a woman out who worked at a restaurant I frequented. But women presume that because you're handicapped, you should be with "your own kind." I know some wonderful women, but all they are willing to do is be friends. Now I accept it and don't go with my urges. You fantasize about the possibilities, but you know what's coming. So instead of losing the relationship altogether, you become friends. I have my music, my apartment, a few friends, everything but a strong relationship with a woman. That will be my downfall. If I didn't have C.P., I know I'd be married and have kids. That doesn't seems fair.

Marilyn Dolmage's Story

I am a parent and live with my family in Orillia. I believe school is so important because it is where children have most opportunities for making friends. Matthew's siblings do not want his future to be dependent on paid people or volunteers. They don't want to look at somebody and think "Are they doing this because it might help them get a job?"

Matthew is fourteen now. One of his friends told me "I like to be Matthew's friend because when I'm with him I don't get in trouble." A lot of kids don't like this guy because he's low status, so they won't come over if he's here. That's a problem for Matthew. At the same time, this kid wanted Matthew to come to his birthday, but his parents said no because there were too many stairs.

We have found older kids are more socialized into the volunteer role. At a recent get-together, one friend introduced himself as a volunteer. I thought that was really strange. We wanted someone close to Matthew's age to help facilitate friends, but grade eight is a really vulnerable age so we had a hard time. Kids around age fourteen are scared to see someone who doesn't have friends and there is no leadership at school to help guide relationships.

We have a circle with kids and adults. The kids had some good ideas about sharing phone numbers, going to leisure activities and cubs, and encouraging carry-over from school. While some of the kids might have an idea -- like sharing phone numbers -- the problem is it has to go through the parents. Matthew might think someone is coming over, but then the kid has to go to grandma's. Sometimes we don't even get a call. So Matthew tries to avoid failure. Sometimes he could be on the street with kids, but he just chooses to sit in his chair at the end of the driveway.

On the other hand, the "Y" here has been a real plus. Matthew doesn't want his worker there -- he just wants to hang out. I think his worker felt uncomfortable there and maybe Matthew sensed this. They have cooking, an after-school drop-in, and a gym program. There is a leader core at the "Y." Three girls from the leader core like to help. Girls that age are more independent. They said "Our group was missing something before -- it's perfect now."

Chapter 3

Ingredients of Friendship

A Friend Is...
On the level of the human spirit, an equal, a companion, an understanding heart is one who can share a man's point of view. What this means we all know. Friends, companions, lovers, are those who treat us in terms of our unlimited worth of ourselves. They are closest to us who best understand what life means to us, who feel for us as we feel for ourselves, who are bound to us in triumph and disaster, who break the spell of our loneliness.

Henry Alonzo Myers

The term friendship is difficult to define, because everyone is supposed to know what it means. It is like a feeling that is hard to describe (Rubin, 1980). As Donelson and Gullahorn (1971) put it, "it may be true of friendship as it is of jazz. If you need a definition for it you'll never understand it." In this book, we describe friendship in its loosest sense, as an affectionate bond between two people.

Bogdan and Taylor stress that acceptance is an important part of friendships between disabled and non-disabled people. Their definition of this kind of relationship is "one between a person with a deviant attribute and another person, which is of long duration and characterized by closeness and affection, and in which the deviant attribute does not have a stigmatizing or morally discrediting character" (1987, p. 35).

Friendship comes in many forms, Barb Goode explains:

> Everybody deserves to have friends. I don't have many that I call good friends. I have learned from my friendships, including the ones that don't last. I have lots who have a disability and lots who don't. Some friends I have known for a long time, even though I don't see them that often but I don't have a lot of close friends. (Barb Goode)

It is also important to view friendship as a process involving numerous social contacts, meeting different people, establishing closer relationships with some people, and, in rare circumstances, having the deepest kind of friendship evolve. Lutfiyya's recent research (1989) confirms this insight into the process of making friends.

Since many different kinds of relationships can be inclusive and accepting, it may be useful to look at the ingredients or qualities of friendship. The following questions may help to focus this task.

1. How important are first impressions, such as appearance, clothing, and behavior, to the development of a relationship?
2. What are the different kinds of communication and how important are they to a friendship?
3. What does a friend do to make the other person feel valued?
4. What are the different ways that each person in a friendship contributes to the relationship?
5. How important is reciprocity for a friendship?
6. To what extent do common interests form the basis of friendships?
7. How much truth is there to the statement that friendships only last when there is the right chemistry?
8. How important is convenience to friendships?
9. Is willingness to put time into a relationship an essential ingredient to friendship?
10. Do friendships require hard work on the part of both participants to make them successful and lasting?

The responses to these questions seem to divide naturally into two main areas: first, several qualities or characteristics that define the broad category of friendship, such as being able to make the other person feel valued; second, conditions enhancing or contributing to the development and maintenance of a friendship, such as common interests.

What Are the Qualities of Friendship?

Participants in various projects and researchers in the field have identified the following major qualities or characteristics that define the broad category of friendship: making the other person feel valued; communicating with the other person; and making a contribution to the relationship or reciprocating the other person's contribution.

Making People Feel Valued and Appreciated

We often refer to a friend as someone who is able to make us feel valued and appreciated (Perske, 1988). Friends have the wonderful ability to put aside any differences or dislikes. They are able to do this in a number of ways: by saying nice things about us, by finding small ways to show how much they care, and by discovering quiet but special ways of communicating, often non-verbally, their feelings for us.

An important element of this is that a friend demonstrates, over time, that he or she is attracted to the person for his or her own unique self (Lusthaus, 1986). Friends let the other person know they are friends because the person is kind, caring, and accepting, not because they have a computer or have rich friends. The friend also makes it clear that the fact that the person has a disability, may be poor, or can't return a lot of favors is not important to the friendship. Children in particular have the ability to see past the disability and accept the person for whom he or she is. This story from a parent illustrates the acceptance children have for each other, which is sometimes difficult for adults to decipher.

> One day we were going to the store with Becky in a stroller, eleven year-old John on his cerebral palsy bike, and Heather. Along came Tonya who didn't know John and said to Heather, whom she knew from brownies, "Oh I thought that (pointing to John) was Jeremy (Heather's macho boyfriend)". I held my breath, assuming there was going to be some hurtful comment about John and his C.P. Instead, Heather says "Are you kidding? Jeremy would *never, never, never* wear a pink shirt." This was an important learning experience for me. Kids aren't all caught up in this disability stuff. They can just see a kid as a person. (Linda Till)

Now that we realize that a friend is someone who is able to make the other person feel valued and appreciated, is there any reason to believe that any person, regardless of disability, is not capable of learning how to show he or she cares about a friend. More importantly, the question needs to be asked, what would be at risk if a person is not given the support needed to learn this important element of being a friend?

Communicating

People often talk about a friend as someone with whom they can communicate. While there are no clear guidelines as to the parameters of good communication, it seems to include: being a good listener; being able to share feelings directly; being honest -- for instance, saying no if the person is not available; and being able to give and receive feedback. This may include not only acknowledging differences but also accepting them (White, 1986).

Many people feel that good verbal skills make it a lot easier for friendships to develop. Emma Pivato's (1988) recent research with school children shows that those with more language are able to initiate more on their own and be more socially acceptable. On the other hand, others have found that while relationship development may be easier for someone who has good communication skills, it is not and should not be seen as a necessary prerequisite.

An important aspect of good communication is knowing, understanding, and using the language and behaviour of friendship. For a child this may mean calling someone a "best friend" and acting accordingly, for example, choosing that person as a playmate over another (Rubin, 1980). These are important skills that are developed in childhood and extended to adulthood if the person has ample experience and numerous opportunities to be with friends.

An understanding of good communication should not be seen only in traditional terms, such as how well a person can speak or articulate ideas. Many people we interviewed emphasized the importance of communication that is more personal or adapted to the particular needs of the friends involved. Often communication between friends is subtle and not well understood by others. This mother's story provides a vivid illustration of the power of non-traditional ways of communication.

> One night at Brownies, they were rehearsing for enrollment and it was boring; the kids were getting restless. Three kids brought Becky over to me and said she said she was sick; ah yes, I thought, they are all bored so this was a good excuse for the three of them to get out of their circle. Shortly after that, Becky started throwing up. I had thought Becky was not reliable enough at that stage for her yes/no communication to work with her friends. But she sent a message and they figured it out. They never even thought to doubt it. They knew she was sick. We cannot underestimate the ability of kids to communicate with each other. They were communicating in an entirely different way. (Linda Till)

This quote also teaches us that when people say good communication is not a necessary prerequisite to friendship development, they may well be referring to more traditional kinds of communication. The kind of communication this parent is talking about may in fact be an important element of all friendships.

Reciprocating Friendship

When people talk about what it means to be a friend, some notion of reciprocity or mutuality is usually raised (Gold, 1986). This includes concepts of give and take, rights and responsibilities, and obligations, all unique and jointly defined within each relationship (Lutfiyya, 1989). Historically, however, people with disabilities have only been seen as receivers. The idea that the person can actually reciprocate another's friendship, improve the quality of life of others, and contribute to the life and well-being of a community is only now beginning to be more widely recognized. This realization has meant that people with disabilities are increasingly able to be contributors (Lusthaus, 1986; Vanier, 1971). The following quote from a parent illustrates the importance of seeing as a contributor someone who has often been considered to be on the receiving end in the past.

> Catherine lives in her own house. She shares her apartment with her friend and roommate. Upstairs is a couple with a child and single woman. A friend who runs a corner store phoned and asked Catherine if they could live in her base-

> ment for a month. Imagine my daughter giving refuge to someone else; tonight they are having a curry supper together. It's fantastic. (Nicola Schaefer)

Unfortunately, some people have been on the receiving end for so long, they simply do not know how to be a friend.

> Sometimes they don't know how to reciprocate or be mutual; no one has expected them to contribute to a relationship ... This handicapped mentality is really just a reaction to the way they have been perceived over the years; but it's not conducive to regular friendships. (Judith Armstrong)

McGee et al. (1987) believe that all people are capable of learning to reciprocate. It is simply a question of teaching this, just as we would various other skills. McGee explains that we can teach people about mutuality and reciprocity in a number of ways, by showing that we value the person, that we want their trust, that we give them the benefit of the doubt. As people begin to trust in a relationship, that is, trust that the kind of relationship that is developing is different from the paternalistic relationships of the past, mutuality and reciprocity will increase. This advocate shares some of the ways that she and her project are beginning to teach people about reciprocity.

> Small things are important so reciprocity can begin, like getting important birthdays on the calendar; celebrating milestones in the lives of family and friends; or helping each person to begin to be a good family member. We've thought a lot about what it means to be a good neighbour because this not only helps in the neighbourhood, but can lead to other relationships. One guy took a jar of his mother's favourite *antipasto* made by the staff, along with the recipe, to a neighbour for Christmas, and it led to unbelievable things. The neighbour started reciprocating. This is learning to be good neighbours, which is the beginning of learning to be good friends. (Leslie McAneeley)

The person with a disability must feel that he or she is contributing to a relationship, not necessarily in the same way, but in ways that are understood by each of the friends. One person may contribute one

thing, such as the ability to provide support or leadership, while the other person may validate the first person's feelings of sense of worth through "quiet acts of thoughtfulness and encouragement" (White, 1986). In this sense, friends play different roles in the relationship. In addition to what may be thought of as a friend's role, they can be volunteers or mentors (Lutfiyya, 1989). The person's contribution also varies according to whether the person has a disability or not, with roles being adapted where necessary. Friends themselves are the best judges of how much reciprocity exists in the relationship. The meaning of reciprocity may differ in different friendships, but if the friendship is genuinely reciprocal, this is what counts. This advocate understands how friends bring different things to a relationship.

> Once people can acknowledge the way their own friendships exist, then they can begin to participate in a relationship with a person who has a handicap; then they will understand that there are lots of different friends, that each provides something else to a relationship; and that they are all valid. (Kim Lister)

Conditions Enhancing Friendship

Both the literature and people in this research talked about conditions that make it more likely that people will meet, that friendships will develop, and that these friendships will be maintained. The things that appeared to be most crucial were: a pleasant first impression, commonalities and shared interests, chemistry, and availability.

A Pleasant First Impression

Several people in the research talked about the importance of first impressions to the development of relationships. While many are hesitant to admit that this can make an important difference in getting one's foot in the door, most agree that a good first impression can create opportunities that otherwise might not be available.

This has been the emphasis of the normalization movement for the past two decades. It has focused on the utilization of means and behaviours that are culturally and age appropriate (Wolfensberger and Thomas, 1983). For example, the way a college student dresses on

campus, wearing polyester clothes instead of blue jeans, could cause them to stand out in a negative way and decrease the likelihood of peers feeling comfortable approaching them.

While acceptance of a person's disability needs to be encouraged, this does not mean that we should overlook encouraging the person to look appealing and trendy as we would other people. Similarly, the way a person greets and interrelates with acquaintances or new contacts should be seen as important. Inappropriate ways of greeting can actually discourage others from pursuing contact or turn someone away altogether. This advocate emphasized the importance of appearance to maximize the potential of a person to meet and make friends.

> The way we look and present ourselves is important. For example, some people leave institutions with poor dental hygiene or bad breath, so we work hard on things that will affect initial impressions. We emphasize a good hair cut and clean teeth -- we have to do this to open up the potential. (Leslie McAneeley)

The danger of this emphasis, however, is that some human services focus too much on people learning so called "appropriate behaviors," often making them a necessary prerequisite for integration. It is important to mention here that clothes and clean teeth do matter, but only in the context of community and relationships. Programs that teach readiness skills and use these to keep people out of their communities and from meeting people who are potential friends contradict the important idea of this book -- that all people have the need and right to make friends immediately, not once the necessary skills have been mastered (Taylor, 1988).

Shared Interests

People often mention commonalities or shared interests as an important factor in how they met or why their friendship continues to be strong (Gordon, 1987). This might include having a mutual friend or a common hobby or interest. Some people have these commonalities before they meet, and the commonality is what enables them to connect. For example, two advocates in Manitoba describe the attraction of a housing cooperative in these terms. "Everyone, with and without disabilities, joined the cooperative for the same reasons -- they

wanted decent and affordable housing and a chance to be part of a close-knit community" (Kappel and Wetherow, 1986, p.4). The common interest then either becomes the focal point for the friendship or gradually lessens in importance as other aspects of the friendship develop and take priority.

Other times, people do not begin with shared interests, but rather start to develop a friendship simply because they are neighbours, co-workers, or classmates. As the friendship develops, they spend more and more time together doing things that are mutually agreed upon. As they share together, not only does their interest in a common activity grow, but their friendship does as well (White, 1986).

When helping a person create new opportunities for making friends, considering the person's interests is a logical first step. If the person thinks of himself or herself as a hockey buff or is interested in politics, for example, then this interest can be used as a basis on which to decide where and with whom contacts could be made. People are finding that when you build on this commonality, it often enables people to bond very quickly with each other (McGill, 1987).

Sometimes connecting people on the basis of common interests is more difficult, especially when their life experiences have been limited. Often, the person's life experiences appear to have been so different from what other citizens experience that it is difficult to believe that two people with such vastly different lives could connect. While it may seem difficult in these cases to draw on a person's interests, this worker believes that there is always an interest, however small, that can be tapped.

> We can always build on a person's interests if we work hard enough, and we must. For example, one woman had lived in an institution since she was four. We got to know her family well and discovered that they used to calm her as a baby with classical music. This was the interest we built on. We reconnected her to classical music; the family was really key in helping us tap this tiny, but important, clue. (Cathie Duchesne)

On the other side of the coin, it may be important for people with limited life experiences to be encouraged to take on interests that are shared by other people in the community. Too often people in segregated settings are learning skills and doing activities in areas that are

not all that common in the community. This parent feels the impact of her son being isolated because his interests differ from those of other teens.

> Doug likes books, computer games, helping with supper, setting the table -- he has all the good life skills he learned in TMR classes -- but these aren't what teens like to do. (Margie Brown)

It may be possible that building on common interests is important because the focus is on the activity or involvement, rather than on the difference that may exist between two people. People in a club or recreational class, for example, generally don't care if a person has a handicap or not. They value the common interest shared among all people in the group who have chosen to come together to explore it.

Availability

Availability is another condition that is vital to the development and continuance of friendships. Three aspects of availability are of particular concern: first, that it is convenient for friends to get together; second, that friends have the time to spend together and put into nurturing the relationship; and third, that both people are willing to make an effort so that the friendship becomes a positive experience.

Convenience

Easy access in terms of location seems to be an important issue for children and their friendships. Children want someone to play with now, not later. It is for this reason that children's friends are often specific to the setting: a child may have one set of friends at day care and another set from the neighbourhood (Rubin, 1980). (The importance of places was discussed at greater length in the chapter on obstacles.) As explained by this educational consultant,

> We are learning about how friendships are formed. If you sit beside someone at school and become friends, you wouldn't have sought that person out if it hadn't been for proximity. Some people meet because of like-mindedness, but others for

little other reason than proximity. So that's really important. (Julie Stone)

In general, adults' friendships are less dependent on close proximity. Adults are willing to maintain close friendship across the city, out of town, in another province, and even across continents. While distance can put a strain on adult friendships, they can often survive despite the distance. On the other hand, proximity can also be an issue for adults, particularly if the friend is going to provide an important support role as well as just be a friend (White, 1986).

> What we have learned is that a way to develop relationships is to be in the same place at the same time. So what we are going to do differently this term is have people more intensely involved in one faculty. For those who have done this, they can now walk in to their faculty building, such as Fine Arts, and know lots of people. They spend a good part of their day in that building and they are becoming known to a large group of people. (Suzanne Frank)

For people whose travel is restricted because of low income, who who have limited access to public transportation, particularly at night, or who lack flexibility because they don't have a car, close proximity of friends can be very important. These kinds of considerations need to be made when thinking of ways to maximize opportunities for friendships to flourish.

Time

Friends have to be willing to put time into a friendship, particularly in the early stages. It takes time for friendships to develop and for people to get to know each other (White, 1986). It is in this sense that friendship can be seen as a gradual process, a journey from the first meeting to a deep, long-term trusting relationship. As people spend time together, they undergo a process of jointly defining their relationship as a friendship (Lutfiyya, 1989). This parent has experienced the frustration of limited time for her son's relationship with his friend, Ron.

> Joe gets very disappointed if Ron is too busy to see him one week, although he understands, because he is very busy himself. (June Kaube)

Everyone agrees that there is no such thing as an instant relationship. Since it takes time for friendships to develop, it is equally important to understand that it takes time to facilitate friendships. Many facilitators of relationships and circles, particularly those supporting individuals returning to the community from institutions, have forgotten what a long, time-consuming process friendship development is, and they may become overzealous in their goals. This human service worker has experienced first hand the importance of moving slowly when facilitating friendships.

> Building friendships and networks can't happen overnight. In Strathroy and British Columbia, the advocates saw networks as an ideal way of giving people supports when they came out of the institution. You just can't build networks around ninety people coming out all at once. Maybe it's more realistic to connect the individual to one person who can be a facilitator to help the person gradually develop several friends. Take it slowly. It takes a long time to build friendships, so don't expect them to appear overnight. (Jamie Hicks)

Each relationship has its own understanding of the time that is required for it to become meaningful and positive. For some friends, seeing each other twice a week is not enough. They still feel they would like to be together more often. For other friends, there is an understanding that both people have limited time due to many other obligations or relationships, but there is a trust that the friendship is genuine and lasting.

> What makes [the friendship] good is that we don't put demands on each other. We enjoy each other's company; it's not based on need. We talk on the phone; but yet it's not a casual relationship; we care a great deal, but it's not the kind of friendship where you have to see each other every day. She knows she can call me anytime. (Linda Morgan)

Effort

Making and keeping friends can be hard work. Most friendships require that both people put a certain amount of effort into keeping the

friendship strong. Without this, the friendship will often fail (CNET, 1987). And as this parent suggests, even when you do work at them, often it is still not enough.

> Just because Brandy is more handicapped, it doesn't mean I have different goals for her. I want her to live independently in the future, to have friends, to do lots of things. It just means it's harder to help make it happen... I have a new baby and I work as a nurse full time, so that means I don't have enough time to work on Brandy's friendships. As soon as I stop working at it, they go away. You do so much but the kids don't come on their own. You get a sand box, do everything you can until you're blue in the face, knock yourself out to get the kids involved and then you don't get a lot back. It's not really her disability or lack of talking that is the problem; it's the amount of energy needed to work on it on our part. (Diana Rees)

With adults, the primary responsibility for putting effort into the friendship is with the individuals. Facilitators may need to do many things on the side lines to be sure the maximum opportunities exist for the friendship to develop or flourish. But it ultimately falls back on the two friends to make the effort for the relationship to work. Lutfiyya (1989) found in her research with adults that in most pairs of friends she studied, both people actively created the friendship together, although it was often the person with the disability who took the initiative to contact the other person.

With children, on the other hand, effort on the part of parents in supporting their children's friendships should not be underestimated. Some suggestions of things that parents can do to enhance their children's friendships, many of which take considerable effort, include (Hutchison and McGill, 1990; Rubin, 1980):

- Meeting and getting to know the neighbourhood children and in turn introducing them to your own child.
- Inviting children to your home or on outings with the family so the kids can connect with your child.
- Ensuring your other sons or daughters do not "take friends away" from the child who is less active or communicative, by setting guidelines; for instance, if the neighbourhood child is the same age as the child with the handicap, the other siblings must allow that

relationship to develop.

- Encouraging other siblings who are close in age to involve the child with a handicap in their play and teaching them ways of building friendships for their sister or brother who needs support.
- Building a good relationship with the parents of the children with whom you want your child to be friends; trying to help other parents understand what they can do to make these friendships work.
- Advocating for your child, if necessary, by talking directly to other children or their parents; for example, if the neigbourhood child considered to be your child's best friend does not invite him or her to a birthday party, you as the parent will have to go over and try to negotiate an invitation.
- Creating an environment at home that will be inviting to other children; even if you as a parent hate things like sleepovers, they are a great attraction and an excellent way to build friendships.
- Teaching children, through stories and discussions, about what it means to be a good friend.
- Acting as an interpreter for the child while teaching the friends how to better understand or communicate with the child; this may include providing alternatives to the way children are currently communicating with each other.
- Providing a good model for other children to learn respect and caring for the child.

While strategies are primarily directed at those facilitating friendships for children, similar suggestions can be made to people who are facilitating friends among adults.

Chemistry

Most people reiterate that even with all the right conditions, if there is no chemistry, the friendship may not happen. "Chemistry," like friendship, is something that cannot easily be described, and the reason people connect seems to be as much an issue of magic and wonder as one of causality. Let any one of us who has unsuccessfully tried to match up two friends on a blind date attest to the importance of letting chemistry be the match maker. This parent describes just how unexpected matches can be.

A few years ago I started a group called "Special Friends" at a nursing

> home. I had a personal sense of some kids being less attractive and responsive, and thus less likely to be chosen by someone to be a friend. But I learned very quickly that you cannot underestimate the ability and power of a person to connect with someone. Many of the least responsive kids were eventually taken home to live by people whose first response to the place was shock and devastation. This was not an intended outcome of our efforts, albeit a very pleasing one. I believe there is someone out there who is going to appeal to everyone; but people need the exposure to connect. (Linda Till)

While we all know intuitively what is meant by chemistry, there is an unconscious belief among some people that it does not natually occur between people with disabilities and those without. This is partly related to an earlier barrier discussed: low expectations infiltrate every aspect of a person's life. When relationships seem to be struggling, we often look everywhere but at the chemistry for the cause of the problem or conflict. We think the person with the handicap is just too much of a burden on the friend; is unable to reciprocate, making the relationship too one-sided; doesn't know how to be a good friend and is turning the person off; or simply is to uninteresting to be with. We think the friend is not committed enough to be a long-term friend of a person with a disability; got into this friendship for the wrong reasons; or has a personal problem with relationships. Most times we ignore the possibility that two people simply are not attracted to each other. This is sometimes a reflection of our inability to see the person with the handicap as we see other people, with the need to have choices in relationships. This advocate states the obvious in a very straightforward way.

> Sometimes the person simply doesn't like the other person; but this could have the perception of lack of reciprocity. It's important to try to help the person sort out what's happening. (Jamie Hicks)

Friendships that occur naturally and voluntarily on both sides will have a greater chance of working.

Linda Till's Story

I am the mother of two children, Jordan, who is three years old, and Becky, fifteen. Becky was adopted at age eleven. I met her in the nursing home where she was living. I have learned a lot about friendship from Becky and her friends.

Kids know what they need to do to get reinforcement out of a relationship, but they might need some help. Becky's friends, for instance, see her laughing as an important response and they have learned how to get her to laugh. That's their contribution. Some friends need a lot less in return than others; some can cope easily and some can't, so you need an understanding of this dynamic.

There is an increased risk with people who have more severe intellectual disabilities that they won't know how to reciprocate. I just spend a lot of time setting basic expectations. I explain to her what she must do if friends come over. I read her books about friendship. I try to bring it to her attention that she has an equal role in the involvement. She is the person who is living her life and she has to take responsibility for it.

The problem of reciprocity is not just Becky's. For example, at Girl Guides she had to learn all the Guide "laws" and tell them which one was the hardest to keep. She was able to communicate to us through our questioning that "to help other people at all times" was the hardest "because they won't let me." She has good comprehension so we can use a yes/no mode to get answers to our questions as a way of communicating. She suggested putting a sign up saying "let me help."

Sonja Clark's Story

I am a student at the University of Alberta in Special Education. I have a close friend named Sherrill, who is twenty-one and lives with her parents. We met through the On Campus program at the University. I meet with Sherrill almost every day on campus. She comes to some of my classes. First of all I check them out to make sure they aren't going to be too boring. Now she's taking educational foundations with me.

I know she values our friendship; she always gets me the most gorgeous cards for Christmas or my birthday. I'm going to be here for a couple of years and I know we will be friends. We're on the phone a lot and we go out at night and weekends. What I really love is the way she has adapted, her independence, and how her sense of humour has improved. She is willing to try new things now. Now she can tease me, which she could never do before. She gives as much of herself as she receives. She's so polite, which is good sometimes because it keeps you on your toes. There is a warmth about her. She's just very nice.

Her parents are thinking of putting her into a group home, but I don't think they realize how much being here on campus has changed her. She's becoming more outgoing and involved in activities. I see a lot of social growth. She can walk anywhere on campus alone now and lots of people know her and say Hi. The only problem is that she wears these polyester pants all the time. I suggested she get blue jeans. At first, she said no. But then I pointed out all the kids wearing blue jeans and she changed her mind. I think it will help her fit in better. I think she trusts what I tell her now. It takes time.

I have changed some of my views on special education. I've never hung around with someone who has a mental handicap, but it changes your outlook. It's hard to describe it, you have to experience it. I wish they would integrate more. When you see how much it has helped her in such a short time, you realize what a mistake they are all making.

Chapter 4

Learning From Different Approaches to Building Friendships

> Friendship is like sex: we always suspect there's some secret technique we don't know about.
>
> *Pogrebin (1987, p.5)*

Many different approaches to facilitating and building friendships have emerged over the past few years. While it is not always possible or even desirable to attempt to categorize them, we have tried to present here the approaches most frequently discussed by those we interviewed and in the literature:

1. One-to-One or Matching Individuals
2. Community Development with Self-Advocates
3. Using Social Networks to Build Friends
4. Bridging to Community

As we shall see, at times, one approach may be used because it seems to be most suitable for the particular circumstances. At other times, an approach is used because it is the only one with which people are familiar. The one thing that is certain is that no one approach alone provides all the answers to the problems and issues regarding friendship (Tyne, 1988). Each may have a place, each has strengths, and each has some weaknesses. What this means is that friendship is not a process that involves a predetermined set of strategies, which if followed, will ensure success. Jeff Stully's warning is an important one: "We need to try many new things and not get locked into one model. There are not all that many new ideas needed; just trying them out and experiment-

ing is what is needed."

Each of the four approaches will be discussed in detail. For each, we will present a brief description of the approach: illustrate the approach with a story from this project that most closely resembles it: and finally, discuss what was learned from the approach.

One-to-One or Matching Individuals

The "matching" approach involves matching or connecting a person who has a disability with another person who acts as a friend, companion, and/or support person. The idea is that if a person has a weak network of friends or family, he or she needs to have at least one good friend or relationship to count on. While having many friends in one's life is generally ideal, this is relatively difficult to achieve for many individuals who have more complex and isolated lives. Facilitating one good relationship is sometimes more realistic. The matches, in most cases, involve volunteer work as part of a formal program (Lutfiyya, 1989).

The approach is not new. The Citizen Advocacy program, originating in the 1970s in Canada and the United States, matched people who were vulnerable and in need of advocacy and support with community volunteers. In many cases, the advocacy relationship evolved into a strong lifelong friendship (Wolfensberger and Zauha, 1973). In the 1980s, "leisure buddy" programs were promoted as a way of facilitating integration and even friendship. Recreation departments recruited youth and young adults to be matched with a person who has a disability. Factors such as close proximity, age, and similar interests were sometimes considered, although difficulty recruiting volunteers often meant any possible match was made. The leisure buddy would then support the individual to attend an integrated program or would assist during more informal participation in the community. The leisure buddy was considered a "friend," despite the discrepancy in age among many individuals in such relationships (Gold, 1988).

Extend-a-Family programs had a similar approach. A family with a child with a disability was matched to another family, preferably one with a child of a similar age. The child with the disability would then visit the "host" family on a regular basis. The focus of the program varied, but usually friendship was seen as the first priority, while respite or parent relief was often a secondary outcome. Sometimes this

friendship lasted for years. In many cases, this friendship was very important for the child with a disability, who often lacked other strong relationships.

All three of these examples of well-established programs have friendship either as a goal or as intended outcome. For this book, an interview was done with Suzanne Frank, a staff person with the Univerity of Alberta On Campus Program. The focus of the program she is involved in is to give young adults who are institutionalized a chance to meet people their own age by attending university classes. Suzanne's account of how her program recruits and matches volunteers is a good example of a recent "matching" approach.

University of Alberta
On Campus Program
Suzanne Frank

I work with the University of Alberta's On Campus Program, which has been in operation since 1987. The main focus of this program is to socially integrate individuals who have been labelled mentally handicapped. Three of the eleven students are severely handicapped and live in institutions. Initially, I wrote letters to every appropriate faculty member and set up meetings before classes started in September. Once there I'd ask for: a list of classes available in the areas the On Campus students wanted, permission to speak to the first-year classes (since all our students were first-year students and we wanted volunteers who were going to be there for four years); and permission for the students to attend classes in the relevant faculty. This happened in both the fall and winter, but not the summer since the summer population is totally different. They are generally older students and the classes are more intense. The On Campus students work for the summer as do many other students.

Sometimes it is better to take a top-down approach, assessing university faculties, arranging a formal interview with a dean. For example, we went to the Dean of Music and he bent over backwards looking into classes, speaking to professors, and finding the most appropriate classes. However, if we sense there is some hesitation, we often choose a bottom-up approach, such as getting a student to tell a professor they want to bring a friend to class.

Students were asked to volunteer at many levels, for instance, as peer tutors in classes they were already attending or in classes selected by the person; socially, during lunch, coffee, or just hanging out; and as facilitators during recreation and leisure activities, such as skating or jogging. There were no specific time commitments required.

Thirty-six university students volunteered after I spoke to classes and asked people if they would like to spend time with an On Campus student. At first, these were volunteer arrangements that operated during the formal 9:00-3:00 office hours of the program, but now many of them (twelve in all) returned for the second term and have continued on as regular friendships are developing. I don't really consider these people to be volunteers anymore. I see clear signs of real friendship developing. Initially, a student might contact me and say "is it OK if so and so and I go to a movie?" Now they just make their own arrangements; we have been able to fade ourselves out of the picture for many people.

What was learned

Over the years, several problems with this approach to facilitating and building friendships have emerged (Hutchison and McGill, 1990; Lutfiyya, 1989; O'Brien, 1987; Wolfensberger, 1983).

1. When individuals do not choose each other, there is a danger that people may be incompatible. On the other hand, both people feel obligated to go along with the relationship once the match is made.

2. While it is often expected the volunteer be a friend, the difficulty of applying the term "friend" to a volunteer is that it diminishes the true meaning of friendship. Volunteers typically act as helpers or support people rather than friends.

3. There has been a strong concern that the formality of the relationship, including time and role obligations, rewards such as a course credit, often interfered with the more natural process of friendship development.

4. Usually the only friendship that emerged from these efforts, if at all, was between the volunteer and the person. Rarely did this

"friendship" extend to meeting others and developing a stronger network of friends.

5. The focus of the relationship other than friendship has a danger of dominating, such as providing parent relief, advocacy, or support for integration.

6. Burn-out of the volunteer is high since he or she may be the only friend, companion, or support the other person has.

On the positive side, many of these one-to-one matches resulted in a great deal of support, intimacy, and companionship between close friends. The fact that many long-lasting friendships emerged from this approach has encouraged these programs to re-evaluate their approach and make changes that reduce the likelihood of such problems occurring. For example, leisure buddies are now encouraged to take on the role of a facilitator of friendships rather than pretending that they are there primarily there to be friends (Gold, 1988).

Interestingly, as many of these changes occur, the one-to-one programs are gradually evolving away from the "matching" approach and are actually beginning to resemble some of the other approaches discussed below. This healthy evolution of an approach is what brings us all closer to making a strong contribution to the relationships and friendships of people with handicaps.

On the other hand, we do not want to imply that all programs must move towards a friendship focus. People need advocates too. If the primary goal is advocacy, or parent relief, then some of these original approaches may still be useful. If, however, a goal is friendship, then a different approach will probably be more useful. The important consideration is that the presence of an advocate (who will probably also be a friend) should not lead to the assumption that the person's friendship needs are met.

Community Development with Self Advocates

The self-advocacy movement is playing an important role in helping self advocates, families, human services, and communities understand the importance of rights, opportunities, and relationships. Self advocates such as Pat Worth are speaking out to help others understand

how important it is that people who do not have disabilities begin to listen to what self advocates are saying, stop doing things to them and for them, and be willing to become involved in their lives.

> We all have the ability to listen ... Sometimes we just don't use it. We just automatically think "I know what is best for this person" ... A friend will listen to our rights and choices. A friend will listen to the person who can not speak for himself because ... they may not say it in words but they can sure say it in expressions. When you don't know people in the community, it becomes frightening because you don't know if you will have a friend there ... We have all had to have people in our lives who support us. It is time to stop punishing us. Give us some friends, reach out and be a friend (Worth, 1988).

With more people now living and working in the community, the possibility and potential for friendships is greater than ever before. Self-help leaders with experience and knowledge have an important contribution to make in terms of teaching others how this can happen. What follows are excerpts from people connected to Rights Now, a project sponsored by the British Columbia Association for Community Living (formerly British Columbians for Mentally Handicapped People), which focuses on self advocacy, personal support networking, and community development through organizing and consciousness raising. Al is the former Executive Director or BCMHP, Kim is the past Director of Rights Now, and Barb is a self advocate and staff person with Rights Now. Their reflections are important because they illustrate the importance of working closely with self advocates in facilitating friendship. They also help us see how relationships are strongly connected with self advocacy and empowerment.

Rights Now
Al Etmanski

> Rights Now has made us realize how unprepared we are for the involvement of people with handicaps. We have found that you can't pursue the notion of personal support and friendship at any level without becoming more sensitive as an organization; if you're serious, you must reflect on yourself as an organization ... I know

that a lot of people with handicaps are on our board because they equate it with friendship; but then they are disappointed because everyone goes home after a meeting and they're back where they started -- alone.

An important strategy is our Self Advocacy Caucus. People with handicaps needed a solid base and some solidarity before telling us what we should be doing as an association. So the Caucus has only people with handicaps on it. By the time they come to the board, they know the issues. We've hired a full-time person to support the Caucus and to ensure participation of people who have mental handicaps in the Association. The person's role is to run interference on all the roadblocks we put up. She reports to the President on how the organization is a barrier for people with handicaps.

Kim Lyster

Barb Goode and I are staff people with Rights Now. The essence of our jobs is to animate; teaching communities to care for their citizens, especially those labelled mentally handicapped. Its foundation has been working with self advocates and then building relationships that would break down the isolation and vulnerability experienced by so many people. This has mainly taken the form of either a personal support network through the Rights Now group or through one-to-one relationships that facilitate involvement in the community.

As people with mental handicaps have become self advocates, and we learned it was a process of "becoming," they began to really understand their oppession. Understanding the power of self advocacy has been a unifying force and a powerful learning experience. We started with speaking to people about their rights and responsibilities but soon learned that deep down most people wanted friends because of how isolated they felt. We also learned that building relationships in the community, either with other self advocates or non-labelled citizens, was ultimately the best way to guarantee rights.

Although lots of people were not well connected, not everyone indicated they wanted support in finding friends. We honoured their choice. In approaching potential friends, we found that some

people wanted to get very formal, as opposed to the casual way the rest of us begin to create friendships. We had to work through this issue and help demystify the process. We also had to figure out where to go to find potential friends. I assure you it's not at the doors of rich people; they prefer the more distanced approach of donations and telethons. Most people who respond have experienced some form of oppression and isolation themselves; they are the ones who reach out. Not surprisingly, the most caring people always seem to be the busiest.

*Barb Goode**

It's so neat to see all those women in the house. They're all so wonderful. They've all changed so much over the year or two they've been there. They're just different people. It sure shows me that they don't need to be living in an institution.

I think, of all the people I work with, one person is really special because I've created a friendship and this person has changed so much. She used to live in the institution, she's non-verbal, and a lot of people felt that there was no way that I could do anything. It had also never happened before that she'd had a relationship with another self advocate. In the last eight months, I've seen such a change in her, from a person who was medicated all the time. She's more alert, she's walking more, and she's gained 15 pounds.

For a while, people were concerned that we couldn't do anything outside of the house without staff being involved because we thought with her seizures it was really unsafe. In the time I've know her, she's never had a seizure when I've been present with her.

We went Christmas shopping. She knew exactly what she wanted to get these two people. And it was wonderful just to see her do it. In January, we went out for dinner with just one staff person. She walked, she ran, she didn't need her helmet and I said to her before we left "Would you like to go out for dinner?" Instead of just sitting there and not responding, she got up in the chair and stopped what she was doing. People thought that she couldn't react before because she was so over-medicated.

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* Barb Goode was interviewed by Linda Morgan.

A final important aspect of self-advocacy groups, which Barb alluded to above, is the importance of having people involved in the self-advocacy movement develop strong friendships with other self advocates. Many people with disabilities struggle with the dilemma of whether to continue to be stigmatized by having involvements and friendships with other people with disabilities, often out of necessity, or whether to fulfill their desire for an informal support system of community friends and family (Rhoades et al., 1986).

While this book has largely stressed friendships with people without disabilities, these quotes from three self-advocates, interviewed by Linda Morgan from British Columbia, reflect how important the self advocate movement is for making friends with fellow members.

> I come to Rights Now meetings to make friends. I get to know their interests and they get to know ours. Most of the friends there need help and they need friends. We just talk about things we want to talk about. I'm amazed at myself that I made more new friends than I made when I was in Langley. I'm starting to understand why we make friends here ... I care, they see it. They hurt, I care for them. I tell them "Maybe you don't have anything worthwhile, but there's a lot of people I know that care for you. I can understand." (Julie Goltz)

> Before Rights Now I felt I didn't have very many friends to do things with ... I like getting together as a group and doing things. I liked the idea of joining Rights Now because I made friends, closer friends. Now that a lot of us are out on our own, we do lots of things, like for instance, we're all going up to Perry's cabin in the summertime. (Janice Ostrum)

> I learn how to get on with people. I don't get mad like I used to a long time ago. I've got a lot of friends now. I feel like I'm more into the group than I was a long time ago. I find that with Rights Now we learn more and more about other people and get to know one another and make friends with each other. (Vernon Point)

What was learned

Only recently, as an increasing number of people begin to trust in self advocacy, are we beginning to learn about the potential of community development with self advocates as a vehicle for supporting friendships (Rights Now, 1990).

1. While developing friendships with valued citizens in the community is the overall thrust of this book, there is no question that friendships with other labelled people, particularly fellow members in self-help groups, play an important part in the lives of people. These friendships are fostered through community development with and by self advocates.

2. Working with individuals and self-help groups as a way of involving them to a greater extent in community groups and voluntary associations as members and decision makers is an important aspect of broadening people's opportunities to meet people who will eventually become friends.

3. Once people are involved, the challenge is to ensure that participation is not token and that true relationships and friendships emerge between individuals who show an interest in each other. This usually requires support and facilitation by people sensitive to the importance of friendships for people with handicaps.

4. There is a danger that self-help groups can become too isolated and segregated, contributing little to strengthening integration and friendships in the community. There seems to be a delicate balance between supporting each other through self help, and cutting members off from connecting with other members of the community. This is a struggle that self-help groups themselves must wrestle with when choosing the direction they wish to pursue.

5. The importance of self advocates playing leadership roles in the community development process cannot be underestimated from the perspective of providing role models or mentor roles to which other individuals with handicaps can relate.

6. Dealing with the fears and anxieties of parents, service providers,

and community members is an important part of this approach to building relationships. Experienced self advocates can provide models and leadership in this area both to those supporting self advocates and to self advocates themselves.

7. Community development with self advocates increases the likelihood that community members will participate with people who have disabilities on the basis of a relationship of equality rather than one of charity or pity.

Using Social Networks to Build Friends

The importance of social networks for friendships and other types of relationships has been written about and studied for some time (Gottlieb, 1985; Wellman, 1983). However, only in the last few years have we begun to realize the importance of social networks for friendships of people who have been labelled as disabled (Forest, 1989).

A social network, in its broadest sense, refers to a group of people connected to any one person, who provide a range of functions in the areas of friendship and support. People may have several different social networks that operate independently of each other, such as one each at work, school, church, the neighourhood, or the community. In this study and in the literature, we have discovered that there are two principal approaches to using social networks to build friends, natural and contrived.

The Natural Approach

The natural approach occurs when people have several existing social networks, such as those listed above, which are used as a way of building or strengthening friendships. For most people who have been living an active life in the community, identifying each of these potential networks is a fairly straightforward process. Sometimes this happens in a very informal way. For example, a parent who is concerned about his or her child's lack of friendships, may look to the church that the child already attends and ask, "what people at the church who know and care for my child, and vice versa, could possibly become closer friends?" Or an adult might say "I've gotten to know a few people at work over the last year whom I like. Which ones do I think

would like to get to know me a lot better and similarly who would I like to become better friends with?"

Using the natural approach does not imply that a person may not still need support to utilize his or her natural networks. In a sense, we all need support around our friendships to maximize the potential of our existing social networks. Sometimes a planning approach is used as a way of determining what supports a person needs. For example, formal planning processes, such as the McGill Action Plan System or MAPS (Mount and Zwernik, 1989; O'Brien et al., 1989), Lifestyle Planning (O'Brien, 1987), or Twenty-Four Hour Planning (Green-McGowan and Kovacs, 1984), are being used by many people as a way of identifying the friendship needs of people and developing strategies to respond to those needs. And sometimes more informal, ongoing planning strategies are used to ensure adequate supports are being provided. Interestingly, these planning approaches can be used here to maximize the more natural social network approach, or in the next section, where more contrived approaches are necessary.

In MAPS, for example, participants in the planning draw a picture of the networks in a person's life, including those with people who are both handicapped and non-handicapped (Cormier et al., 1986). Significant barriers to integration or friendship that are evident in any of the environments are identified. Participants dream with the person about a possible future. And strategies for developing new friendships or strengthening already existing relationships in one or several of the person's networks are created. We have included an example of the strategies that emerged from a MAPS session used by a family to do some short-term planning in the areas of friends, independence, and communication. This illustrates the usefulness of a planning process that is consumer and family driven, holistic, and action-oriented. The following is an excerpt from a more extensive document of the planning process (Dolmage and Luckett, 1986).

Matthew's Chariot:
Strategies for "Friends"
Dolmage and Luckett

Getting to know the neighbours:

- Exploring the neighborhood on his own terms on his mobie [wheelchair], or walking

· Planning family parties with different neighbourhood families (writing invitations himself)
· Possibly sharing the family paper route on Tuesdays
Who: Marilyn and Jim

Day camp:
· Orientation meeting scheduled with coordinator – discuss Matthew's interests
· Opportunities for choices in activities and associations
· Recognition as a senior camper – find ways he can help
· Communicate with Mathew and camp staff about emerging friendships
Who: Marilyn, Jim, and Matthew

Spontaneous casual outings with Leah and/or Jay:
· Errands to nearby stores
· Friends' homes
Who: Leah and Jay

Weekend activities with Heather:
· Usually includes another child, e.g., Brad, Steven, Kim, new friends, siblings
· Trips around Orillia, e.g., restaurants, arcades, parks, stores, movies, bowling
· Matthew's choice encouraged
Who: Heather, Marilyn, and Jim

At home:
· Share music
· Swim in pool
· Introduce more word games, e.g., Scrabble, Spelling Bee, sleep over
Who: family

Looking ahead to Cubs:
· Research Scout units re: accessibility, school mates, and flexibility
· Be prepared to discuss with larger circle choice of Cubs versus Scouts
Who: Arleigh

Finding a new special services worker:
- Heather will not be available as of September
- Arleigh is too much of a mother figure for recreational integration
- We feel a young man would be more suitable.
- Matthew to participate in interview
- This person should be part of the next circle meeting

Who: parents and Family Resource Worker

The literature and experience from support circles is growing and can teach us a lot about friendship. For example, "seven truths" about support circles include: no two support circles are the same; circles often form around two people where an advocate speaks for the challenged person; circles usually form where the person himself or herself wants change; the person grows in direct proportion to the commitment of the circle; if circles are too small, everyone is under pressure; circles often start during a crisis when the person is least willing to tolerate his or her situation; and a facilitator is often needed to help the person express what he or she really wants (Forest, 1987).

The Planned Approach

There are many individuals who have few or no existing social networks that can be used as a way of building or strengthening friendships. For most people who have been living very segregated and isolated lives, the only personal contacts they experience are with other people with disabilities, usually in services, the staff or professionals who run the services, and possibly some family members. In these cases, it is not possible to rely on these existing networks as a strong source of future friendships.

What some people have been trying to do is to create a new social network around a person. It is in this sense that we say the social network is planned and somewhat contrived. Again different approaches are used. For example, sometimes the social network is made up of professionals and some people from their own personal networks (Jamieson, 1988). Sometimes individuals who don't even know the person are invited to participate in his or her life. Settings such as churches are seen to be more receptive than others for recruiting volunteers. Other times, a combination of exisiting acquaintances and

either totally new people or the acquaintances' friends are brought together to build a social network around the person.

This approach has recently become known as building a circle around a person (Forest, 1987; Mount et al., 1988a; Mount and Zwernik, 1989; Ruttiman, 1987). For an engaging collection of stories about the lives of several people and their circles of support, see Perske's (1988) book called *Circles of Friends*. Since a formal network is often useful to get services in place, or particularly to get people through a life transition, some feel that it is logical that a formal network might also be useful in the area of friendship.

> The circles are more formal with the older kids. These kids have come through a segregated system and it's different. And the other kids need to be educated. (Cheryl Elliott and Jenn George)

While some argue that friends are sufficient to provide support, those who make use of circles have found that it is important to sort out in their minds whether the circle is needed primarily for support or for friendship. Jamie Hicks's story about his involvement with the Joshua Project in Calgary is very useful because it shows how important it is to sort out the difference between support circles and friendship, as well as when each is needed.

Joshua Project in Calgary
Jamie Hicks

I worked for the Joshua Project, which is sponsored by the Calgary Association for Independent Living. We learned that there needs to be flexibility in models. When we started with a number of folks who were in jeopardy of being institutionalized, we were very protective. We had rock bottom support groups to protect them from society. It's similar to the way in which Judith Snow got started. At first the groups were very formal to help us through the crisis or transition. Then they became more informal once services were in place. Now we don't meet formally as a group. Not every single person considers himself or herself to be a friend; on the other hand, some were friends before it started. We found that if people don't become friends, they usually leave the support group

after the crisis blows over. It's usually the professionals who leave.

Another example of why there is no set model is the story of a woman whom we were having difficulty supporting. Once we found out she was gay and that most of her supports were in the gay network, we were able to facilitate; but in our context she felt totally isolated. She needed a much more informal network of friends.

It is important to distinguish between friendship and formal support networks. The latter play a very important role in organizing and ensuring services, such as a monitoring mechanism. For example, one guy would not have received his pension if he hadn't had a support network. In another case, a man had a support group started by his parents with some of their friends. But he didn't like to come because he knew it was primarily for his parents and he didn't like being talked about. When he needed support, he actually called other people.

Sometimes circles lead to friendship and sometimes not. But providing support can interfere with friendship. Usually once a crisis is over, the friendship can resume and is sometimes even stronger. I had a woman live with me, who was grieving, so we had to support her through this. I was trying to be a friend, but was having to support her in getting her money to get services. I was actually providing the services. I was relieved when she moved out. There is a danger of running out of energy for the friendship.

What was learned

The use of social networks to build friendships for people who have a disability appears promising. The main reason for this is that it is generally one of the most important ways that citizens meet and make friends. The more integration and community a person has in his or her life, the more natural this process of drawing on social networks can be. However, concerns with this approach arise when people's lives are segregated and isolated and therefore approaches to using social networks become more contrived (Hutchison and McGill, 1990; Mount et al., 1988; Perske, 1988).

1. If a person's social network becomes too dominated by professionals or people who don't know the person, the person will be left at risk of having few friends, the very reason the network was developed in the first place.

2. While it is understandable that some planning is needed some of the time for some individuals, the risk is great that friendship will become just another desired outcome of the multitude of formal planning processes that exist in the lives of people who have been labelled handicapped.

   The issue of friendship has become a new religion. It's going to be a challenge to figure out how to work on this at the same time as safeguarding it. [Models such as] Individual Program Plans (IPP) and Individual Education Plans (IEP), and even Joshua Committees, will have friends as an outcome. But with all these models, we see a lot of potential perversions. (Jeff Strully)

3. If the planning process is initiated and controlled by the family or individual, it has the potential for being positive and useful. If, however, it is controlled by professionals, there is serious potential for abuse.

   One of the things that frightens me is the thought of agencies using support networks, like IPPs, as a means of accountability or to get work done they can't do themselves. It's the institutionalization of a concept and it will have negative effects. (Jamie Hicks)

4. Because things like friendship circles have gained much popularity, there is a danger that people will think everyone has to have one, whether it is needed or not. Other more natural approaches may be available but not considered because we just assume that everyone could benefit from having a circle.

5. There is sometimes too much focus on the size of a support network because of the assumption that, if people do not have a large circle or support network around them, the process has been a failure and the person will be left vulnerable. Research shows it is the intensity of the relationships, as well as the size, that constitutes effective support (Gottlieb, 1985).

6. If friendship is seen as the only goal, when friendships take a long time to emerge, the individuals will often experience frustration.

This quote shows how it is possible to make friendship secondary to some other focus of a social network.

7. Friends themselves will often need support, so it may not be to anyone's benefit to separate out the issues of support and friendship. A parent makes this important point.

   I think that support circles need to support all the people in the group, not just the person. Some say you need to decide who needs a circle, the individual or the family -- well I'm adding one more aspect, a circle for the circle. The person can be the major focus, but everyone needs to know that there are equal relationships among all members of the circle. The relationships need to be mutual and involving. (Linda Till)

8. Some people feel that focusing on friendship to the exclusion of other important kinds of relationships is a very big mistake.

   After a year and a half we've come full circle from where we started. At first we thought in terms of friendships and support networks. Now we realize that was a mistake. We believe the focus should be on social relationships. The concept of friendship is too limiting. If you focus only on friends, that could limit the development of relationships with the person' family . We have to get back to our original purpose about relationships, even if it is at the same time as still doing some of the other necessary things. (Cathie Duchesne)

9. Like all the approaches, people experience frustration and limited success if the focus is restricted to one single approach rather than understanding and considering a range of approaches.

Bridging to Community

Another approach being used by a growing number of people to build friendships is known as the bridger or connector approach. The assumption is that people who are isolated need someone to guide them into the community and to people who will be their friends. In this sense, the bridger approach introduces the person to new places, guides

the person to new relationships, connects the person with valued citizens in the community, familiarizes the person with new opportunities, and brings the person out of isolation into community life (Hutchison and McGill, 1990).

The bridger approach is based on two assumptions, both of which were discussed in detail in Chapter Two: first that people with handicaps have the right, need, desire, and ability to be friends with a range of people; and second, that our communities have the capacity and willingness to become involved with people with handicaps as friends. The bridger approach makes both of these assumptions and gets on with the important task of guiding people out of isolation and segregation into community.

Understanding the Nature of Community

An important aspect of the bridger approach is the need to understand what our communities are. As dicussed in Chapter Two, an understanding of community requires that we distinguish between human services and community. Human services are the more hierarchical, organized, controlled aspects of our society that are organized to meet the needs of people though formal mechanisms. Community, on the other hand, is more informal, cooperative, and people-oriented.

The concept of "associations" for building friends encourages the use of small, informal community groups and associations, as well as connectors, as a way of linking a person to the community and friends. John McKnight (1987) believes that if each of us has a social map of our community, then it would be seen as a social place to be used by individuals, family, friends, and the community. He has developed an "associational map" of his own community to illustrate how others can do this. It includes every possible community group that people could be involved in, but not human services. For example:

Artistic Organizations: Choral, theatrical, writing
Collectors Groups: stamp collectors, flower dryers
School Groups: printing club, PTA, child care
Youth Groups: 4H, Future Farmers, Scouts, YWCA

It is believed that one important way of promoting participation in the community is through membership and involvement in more informal community groups, clubs, and organizations. This is a two-step process of, first, finding out what groups are available (Commu-

nity Life Project, 1988); and, second, getting connected to individuals in the groups and forming close relationships (Mount et al., 1988a).

Being in Integrated Settings

The greater the number of environments the person is exposed to, the greater the chances of connecting to a range of potential friends. In other words, it is important that the person have access to places that are frequented by many other people to increase the possibilities for friendship (Strully, 1985; Strully and Strully, 1985). This makes the role of the person acting as a bridger easier.

> The more places you frequent, where you have the potential to meet connectors, the more friends you will have. This does not happen in sheltered workshops or segregated bowling leagues. People need to be doing valued activities, so people there can connect them. If fitness is the "in" thing, we should be there. Then you can meet someone who has a common interest and it will give you an opening. You can initiate by saying something like "Let's go for a coffee after class" or "My friend here just moved from Red Deer. Could you take some time to help us get to know this club?"
> (Leslie McAneeley)

> Her plan is now more individualized, sort of an off-shoot of Jeff Stully's idea about options. She spends two afternoons volunteering at a daycare and they love her there; two afternoons swimming, with the idea of it eventually leading to a job helping to hand out towels; and I'm trying to get her into the Praire Theatre now. This approach cannot help but to connect Catherine with potential friends.
>
> The second thing is to live with people who are friends and will help you with friends. Catherine's housemate Darlene and the others in the house are a really good connection. Catherine has friends because Darlene lives with her and has lots of friends and wants them to meet Catherine. She has good friends; and friends of friends. It gives her spontaneity in her life. She has done some really exotic things. Friends just call when they are going somewhere and ask her to go with them. An Indian friend who was going to his parents'

fiftieth wedding anniversary invited her to join him.
(Nicola Schaefer)

If a person's life is only partially or poorly integrated, integration is an important initial step, perhaps at first in just one area of the person's life, through leisure and recreation pursuits (McGill, 1987); by getting to know people in the neighbourhood and community (White, 1986; Leslie McAneeley); by using already existing networks, such as church, to start building relationships (White, 1986; Marilyn Dolmage); or even by moving to or having access to an existing integrated school system (Margie Brown; Marilyn Dolmage). These new environments will provide the context for developing friendships that are based on shared experiences.

I decided the college was not the best place to meet people. The community college has 6,000 students who are all in a hurry to finish in two years. The students just didn't have time. It's not a social college, where people can really get to know each other. A university education is a broader learning experience about life and how to get along. This might be better for Catherine.
(Nicola Schaefer)

They used to have a program like this at Grant McCuen College but it flopped. It's better here anyway. The image at the university is much better. I remember the awe I felt when I found out I was going to be able to go to university. All my peers are the same. Of course once you get here you realize it's not that big a deal. (Sonja Clark)

It is important to make use of natural settings, where there are others the same age as the individual. Since friendship development through natural settings is such a different focus, it necessitates the involvement and education of families so that the living and home environment can be as supportive as possible. For older parents to have confidence and trust, they need to see these new concepts work for their son or daughter before they feel really supportive. There often seems to be a gap between someone cognitively understanding the concept and actually applying it to their personal situation (Cormier et al., 1986).

Finding Bridgers

There needs to be an emphasis on finding people who can act as bridgers, guides, or connectors. Knowing the qualities of bridgers is a very important part of finding them. Some of the qualities that seem to be important include the ability to: focus on the gifts, fullness, capacities, and contributions of people rather than their deficiencies; work by trust, not authority, in connecting; believe that the reason people with handicaps are not in the community is because no one has asked them to join; and be willing to let go after they have guided someone into the community (McKnight, 1987; O'Connell, 1988). The following concern raised by a bridger illustrates the importance of one of these qualities.

> I don't have a real social life. I have three kids, aged twenty-one, five, and three, and am a single parent. I know most of my friends through the college or Rights Now. My neighbour knows Deb quite well; but most of her other friends are casual. I am quite a different age from Deb so it's a problem in terms of connecting her. (Linda Morgan)

Building Bridges for Individuals to their Communities

Once in an environment with others, the next strategy people emphasize is something called "connecting" -- connecting individuals to others who themselves have lots of connections. Having one friend can have a ripple effect; that is, you often become a friend of a friend.

> Students in the program are not registered at the university. They audit any courses they take. Most of the courses people take are lab courses in drama, music, and introduction courses in psychology. The other people there constitute one of the most important elements. They are the ones who the person will connect with. (Suzanne Frank)

> The program has its base in the education building, which I think is especially good for the education students. They need this kind of experience. And it's good for the students with handicaps because they have a place they can see as their own. I know a lot of people and I have been able to make a lot of connections. (Sonja Clark)

With the younger kids, the older kids from grade 8, for instance, go in and act as supervisors at recess and encourage classmates to play with them. In other cases, we have provided an alternative to cliques -- the leader in the class will befriend the kid and then others follow. We encourage the mature kids to get involved. They encourage others to follow and this helps with the kid's credibility. (Cheryl Elliott and Jenn George)

Leslie McAneeley's story of her role as a broker and connector for people coming out of institutions in Alberta is a wonderful illustration of how the concept can work. A broker is a person who works with and on behalf of a number of individuals, assisting them in accessing the services and supports they desire.

Brokerage in Alberta
Leslie McAneeley

I am a broker for several individuals coming out of institutions. The idea of connectors is very important. In a high school, a young lady volunteered to help connect Mark. I followed her around some weeks later and realized that we were not the best connectors. *She* was a real connector. Hundreds of people said hi to her and Mark. In checking, I found out she's popular at school, but not a valued academic student. I know Mark used to be involved in a work experience program at lunch but now he goes with her to the mall instead. All the merchants there know her; she is "Connector Tammy." I wish I had a counter for the number of kids she connected Mark to at school and at the mall. Today she helped him get a summer job (without asking his parents). Being connected to someone is very cool.

She came forth; our magical formula didn't get her. But if he ever needed someone to hang out with, despite the fact that the teachers wish she was more academic, she is the person. Her latest plan is convincing Mark to skip classes with her. We can't say yes, but what a great opportunity for him, something no kid should miss in highschool.

We have to look for connectors, people like Tammy. Every community has them. That doesn't mean we don't want staff to be

connectors; it should be one of their many skills, but we should use the people who already exist in our communities, who are naturally connected.

We encourage paid staff to use their own networks. Once I heard someone say "A staff member took John to his family picnic on work hours and that's not fair." But what a great idea to value John enough to take him to your family picnic. Or if staff share an interest, it's a chance for the person to see if they also have this interest; then the staff can start to connect. Some of the staff are artistic, have a flare for life. Our hope is that some of that flare will rub off on the person who hasn't been valued. So you can see, we also put a heavy emphasis on the paid people so that they will aggressively and creatively pick up on the concept of relationships and begin to help encouraging them and supporting them.

What was learned

Because this is perhaps the most recent of the approaches, what we have learned is still relatively tenuous. However, certain issues have arisen with regard to the way in which we should connect people to their communities (McKnight, 1989; Mount et al., 1988; O'Connell, 1988).

1. As with all of the other approaches, there is a concern that people will focus too much on the bridger or connector approach, and this will result in frustration or creating opportunities that are too narrow. In other words, not all people's needs can be met using this approach.

   I'm worried that many of us our age are too busy with work and family to be involved in community associations; and we don't want the person just to be an active association member. If people think that all we have to do is connect people to associations, that it will immediately be the door to community or to friendship, they might be disappointed. Once people are into associations, are they really getting to be friends or are they going their own ways after meetings? Sometimes yes, sometimes no. (Jeff Strully)

2. The above quote illustrates another problem: the focus on associations. In the chapter on barriers, we discussed the problem of

focusing too much on formal recreation programs, many of which never lead to friendships. A similar danger exists when focusing on community associations. Unless supports are built to ensure that relationships develop, we could have a lot of people who are initially hopeful, then later disappointed, floating around in community clubs and associations.

3. When the necessary qualities of a bridger are not taken seriously, and any number of other people, including professionals, are assigned the job of bridging or guiding people into the community, the approach is compromised and people's opportunities for connecting with the community and building friendships are at risk.

4. It is very easy for bridgers to stop when one friendship has been developed with a person, making the relationship susceptible to many of the same problems experienced by one-to-one relationships discussed in the first section of this chapter.

5. Sometimes the bridger becomes distracted by becoming a friend, compromising his or her important role as a bridger.

6. It is very easy for the bridger to get caught up with the more basic needs of the person and feel that any efforts at building friendships need to be put on hold until housing, financial, or safety needs are attended to. What we have learnt, however, is that a strong network of family and friends helps to ensure that fewer crises arise, and when they do, there are plenty of committed friends ready and willing to assist.

Conclusion

This book is about the importance of friendship for people who have been labelled. It outlines the obstacles that inhibit people with labels from making friends, specifies the elements of friendship, and describes different existing approaches to developing this kind of relationship among people with and without disabilities.

Perhaps the study's most basic principle is that friendship plays as critical a role in the lives of people with disabilities as in those of people everywhere in the community. Indeed, the need for friendship is accentuated for people who are labelled because of the numerous obstacles they experience throughout their lifetime. Many have been segregated in all or most aspects of their lives, and many spend the greater part of their day in formal services of one sort or another. This makes it virtually impossible for them to participate in or make any meaningful contribution to their communities. It also seriously restricts the possibility of developing relationships with other community members, not least because those who are labelled are rarely provided with the opportunity to learn the skills needed to make friends.

Understanding and defining the elements and dynamics of friendship has proved an invaluable exercise for building friendships between people with disabilities and others in the community. On the surface, this approach may appear obvious or irrelevant. However, given the low expectations our society has of people who are labelled, it is important to show that members of this disadvantaged group are in fact equally capable of developing the skills needed to have and be a friend. Specifying the different elements of friendship makes this task easier.

Numerous interviews and an examination of the most recent literature on friendship and community makes clear that there is no simple recipe for building relationships between people with labels and other members of the community. Each situation must be approached in a unique way, depending on the people involved, their interests, their supports, and the nature of the community. We have been facilitating the development of friendship for some time. We have had some success, but have also often intervened in ways that we now realize are limiting to people. It is important that we take the time to evaluate these different experiences and perspectives, learn from our mistakes

and our achievements, and be willing to move on to other more effective approaches.

Developing friendship between members of the community and isolated people who have a disability opens up new hope and possibilities for the future. It offers us a way to make our communities and society more humane, responsive, and accepting of diversity.

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Appendix A

Individuals Interviewed for Project

Judith Armstrong
Executive Director
Victoria Handicapped Recreation Society,
Victoria, B.C.

Margie Brown
Parent, Advocate, and Professor
Acadia University, N.S.

Sonja Clark
Friend and Student
University of Alberta,
Edmonton, Alta.

Marilyn Dolmage
Parent and Advocate
Integration Action Group,
Orillia, Ont.

Paula Dorval
Parent and Volunteer
Steering Committee of Personal Support Project
Edmonton, Alta.

Cathie Duchesne
Staff
Personal Support Project,
Edmonton, Alta.

Al Etmanski
Former Executive Director
British Columbia Association for Community Living
(formerly British Columbians for Mentally Handicapped People)
Vancouver, B.C.

Cheryl Elliott and Jenn George
Teachers
Waterloo County Separate School Board,
Kitchener-Waterloo, Ont.

Victor Fenton
Self Advocate
Dartmouth, N.S.

Julie Goltz
Self Advocate
Vancouver, B.C.

Suzanne Frank
Staff
University of Alberta On Campus Program,
Edmonton, Alta.

Geraldine Gertz
Self Advocate
Winnipeg, Man.

Barb Goode
Former Staff and Self Advocate
BCMHP Rights Now Project,
Vancouver, B.C.

Jamie Hicks
Former Staff
Joshua Project,
Calgary, Alta.

June Kaube
Parent and Advocate
BCACL Rights Now Project,
Vancouver Island, B.C.

Kim Lyster
Former Director
BCACL Rights Now Project,
Vancouver, B.C.

Zana Lutfiyya
Researcher and Advocate (a Manitoban)
Syracuse University,
Syracuse, N.Y.

Leslie McAneeley
Broker and Advocate
Personal Support Community Association,
St. Albert, Alta.

Linda Morgan
Friend
Vancouver, B.C.

John Nevard
Self-advocate, author of unpublished manuscipt
Kitchener, Ont.

Janice Ostrum
Self Advocate,
Vancouver, B.C.

Emma Pivato
Parent and Professor
University of Alberta,
Edmonton, Alta.

Vernon Point
Self Advocate,
Vancouver, B.C.

Diana Rees
Parent and Advocate,
St. John's, Nfld.

Nicola Schaefer
Parent and Advocate,
Winnipeg, Man.

Julie Stone
Consultant, Department of Education New Brunswick
Woodstock, N.B.

Jeff Strully
Parent and Advocate
ARC, Colorado

Linda Till
Parent and Advocate
Sharon, Ont.

Bob Walker
Professional and Volunteer
CACL Board of Directors,
Whitehorse, Yukon

Appendix B

Methodology*

The methodology of this study was designed to understand friendship from the perspective of people concerned with developing and facilitating friendships for people labelled mentally handicapped. In addition to a detailed search of the literature, thirty key informants from across Canada were identified and interviewed for this study. All the key informants had experience in friendship either as facilitators, researchers, friends, or relatives. They included: parents (9); self-advocates (7); friends (2); and advocates and professionals facilitating friendship through deinstitutionalization and other integration projects (12).

An in-depth open-ended interview was conducted with each person. In the interview, the researcher encouraged research participants to relate their stories and experiences about friendship. Throughout the interview, the researcher asked probing and clarifying questions related to the research goals.

A five-step qualitative process of analysis was designed to ensure that patterns and themes that might emerge from the data could be carefully verified. These included: transcribing the notes from the interviews; coding the data with key words as a way of identifying commonalities and variations; identifying common and variable patterns; and identifying themes that link or explain the data (Lord and Hearn, 1987; Miles and Huberman, 1984; Patton, 1980). In addition to the interviewing process, most key informants were sent a draft of the report to comment on whether their perspective was represented in an accurate light.

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* *The results of this study are available from the Proceedings of the Sixth Canadian Congress on Leisure Research, University of Waterloo, Waterloo, Ontario, 1990.*

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